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ABSTRACT

This publication is a compilation of papers presented at an April 1994 workshop sponsored by the National Center for Education in Maternal and Child Health and the Bureau-funded Johns Hopkins Child and Adolescent Health Policy Center (CAHPC). The papers are as follows: (1) "Defining the Issues and Planning for Change: Health Care Systems, Primary Care, and Reform" (David Heppel); (2) "Health Care systems and Primary Care for Children and Adolescents: Overview and Context" (Bernard Guyer and others); (3) "Delineating Public Roles in Planning, Providing, and Evaluating Primary Care Services for Children and Their Families: Les Nouveax Miserables--Modern Victims of Social Asphyxia" (David R. Smith); (4) "Assessing the Status of Primary Care Services: A Working Approach" (Barbara Starfield); (5) "Developing Population-Based Datasets at National, State, and Local Levels: Potential and Promise" (Deborah Klein Walker); (6) "Assessing the Status of Primary Care Services: Early Experiences of the Child and Adolescent Health Policy Center in Evaluating Primary Care" (Charlyn E. Cassady); (7) "Assessing Needs and Monitoring Progress in the Delivery of Primary Care Services for Children and Youth" (David M. Stevens and others); (8) "Community System Assessment and Child Health Planning in Iowa" (Charles E. Danielson and others); (9) "Evaluating the Delivery of Pediatric Primary Care in New York City" (Lucille Rosenbluth); (10) "Accountability in Primary Health Care Systems: Conceptual Frameworks and Policy Challenges" (Bernard Guyer and others); (11) "Primary Care Provider and System Challenges in Caring for High-Risk Children and Families" (Larry Culpepper); (12) "Meeting the Contemporary Needs of Children and Youth with Developing Primary Care Systems: Issues for Pediatricians in Health Care Reform" (Susan Aronson); (13) "CHIP--A Community Model for a Comprehensive Health Care System" (Peggy Balla); (14) "Pediatric Primary Care Systems Development Initiatives in Arizona" (Jane Pearson); (15) "Health Care Reform and Public Health Consideration in Alabama" (Larry Menefee); (16) "Public Health and Health Care Reform: Healthy People in Healthy Communities" (Martin Wasserman); (17) "What's Needed to Move Forward? State MCH Program Perspectives" (Maxine Hayes); and (18) "Commentary and Closure" (Bernard Guyer). Two appendices include the workshop agenda and a list of participants. (DR)

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ED 392 537

Assessing & Developing Primary Care FOR Children

REFORMS IN HEALTH SYSTEMS

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REFORMS IN HEALTH SYSTEMS

Edited by

Holly Allen Grason, M.A.
Bernard Guyer, M.D., M.P.H.

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The Child and Adolescent Health Policy Center (CAHPC) at The Johns Hopkins University was established in 1991 by the federal Maternal and Child Health Bureau as one of two centers to address new challenges found in amendments to Title V of the Social Security Act (MCH Services Block Grant) enacted in the Omnibus Budget Reconciliation Act of 1989 (OBRA '89). The purpose of JHU CAHPC is to draw upon the science base of the university setting to help identify and solve key MCH policy issues regarding the development and implementation of comprehensive, community-based systems of health care services for children and adolescents. Projects are conducted to provide information and analytical tools useful to both the federal Maternal and Child Health Bureau and the state Title V programs as they seek to meet the spirit, intent, and content of the Title V legislation and the challenges of addressing the unique needs of MCH populations and programs in health care reform. CAHPC is located at The Johns Hopkins University, School of Hygiene and Public Health, Department of Maternal and Child Health, 624 North Broadway, Baltimore, MD 21205. Phone: (410) 550-3443.

The mission of the National Center for Education in Maternal and Child Health is to promote and improve the health, education, and well-being of children and families by leading a national effort to collect, develop, and disseminate information and educational materials on maternal and child health; and by collaborating with public agencies, voluntary and professional organizations, research and training programs, policy centers, and others to advance knowledge in programs, service delivery, and policy development. Established in 1982 at Georgetown University, NCEMCH is part of the Graduate Public Policy Program. NCEMCH is funded primarily by the U.S. Department of Health and Human Services through its Maternal and Child Health Bureau.

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Acknowledgments

No single policymaking entity or health profession alone can hope to appropriately address the contemporary needs of children and youth. As participants in a multidisciplinary field of inquiry and practice, MCH professionals thrive on partnerships. The presentation of this workshop and the publication of these proceedings is no different. Three organizational institutions hosted the efforts of several dozen people who were vital to the endeavor. While we as editors wish to acknowledge the contributions of each of these colleagues, we also note in this context a theme of the workshop related to systems—*the whole is greater than the sum of its parts*. A special synergy evolved from the start of the workshop planning in 1993, through completion.

From within The Johns Hopkins University Child and Adolescent Health Policy Center (CAHPC), Barbara Starfield served as co-chair and worked with us and other members of the Center faculty—Charlyn Cassady, Mona Shediac, and Donna Strobino—providing guidance throughout. CAHPC staff Alyssa Wigton and Lori Friedenberg translated plans and materials into graceful activity. Members of the CAHPC State Cluster Group—Charles Danielson, Sally Fogerty, Maxine Hayes, Cathy Hess, Jane Pearson, and Tom Vitaglione—provided guidance in development of the workshop content and agenda, as well as translation of the proceedings into resource materials for state MCH programs.

The National Center for Education in Maternal and Child Health (NCEMCH) provided logistical support for convening the workshop, and editorial and graphic support for producing this publication. Their creativity, expertise, and patience with our academic culture made it work. Rochelle Mayer and Laura Kavanagh provided administrative leadership. Paula Sheahan and Susana Eloy organized the workshop logistics, making sure all the while that we were comfortable and productive. Our wonderful wordsmith, Jeanne Anastasi, edited the 18 papers and accompanying text that comprise this publication. We are grateful, too, for the talents of Kenna French, who added her artistry to our efforts as graphic designer for this book. Christopher Rigaux, Carol Adams, and Marcos Ballestero also were instrumental in the production of the workshop materials and proceedings.

The Maternal and Child Health Bureau's Division of Maternal, Infant, Child and Adolescent Health (DMICAH) informed, encouraged, enlivened, and funded all aspects of this work. DMICAH Division Director David Heppel's commitment to bringing together the thinking and work of academicians with public and private MCH practitioners saw us through the process.

Finally, our special gratitude to the colleagues who prepared papers and presentations for the workshop and challenged our thinking throughout. We cannot thank them enough.

Preface

A number of powerful forces converged in the early 1980s to precipitate unprecedented changes in the delivery and financing of medical care in this country. Runaway medical inflation led to numerous cost containment initiatives. The severe economic downturn, experienced in almost every state, contributed to higher rates of uninsurance and underinsurance. Concurrently, many indicators of health status declined, particularly among populations of women and children. By mid-decade, Congress acted to respond to concerns about declining maternal and child health status and decreased access to health services by authorizing annual incremental enhancements and expansions in the Medicaid program. For the maternal and child health (MCH) community, congressional action was punctuated in 1989 with sweeping changes to both Medicaid and Title V of the Social Security Act, specifically in the area of child health services.

Policy challenges found in the 1989 Title V amendments contained in the Omnibus Budget Reconciliation Act (OBRA '89) involved a new focus on meeting the primary care needs of the population along with new specific mandates for developing community-based systems of care and more explicit requirements for carrying out public health assessment, reporting, and other data-related functions. These statutory changes presented both conceptual and logistical challenges for the state-based MCH Block Grant program.

Concurrently, the pace of change in medical care and financing accelerated to the degree that "health care reform" took center stage in 1994 as an issue of national policy concern and debate. In addition, state governments, professional organizations, the business community, and major health care provider institutions independently engaged in self-examination and significant deliberation and activity to determine new directions needed to address health system reform issues.

To address these changes and challenges, the federal Maternal and Child Health Bureau (MCHB) initiated activities on a number of fronts to assist states in implementing the spirit and mandates of the OBRA '89 amendments to the Title V program. These activities include:

- Establishing the State Systems Development Initiative (SSDI) grant program, which provided funds above the MCH Block Grant formula allocations for developing state capacity specific to primary care and systems development responsibilities;
- Convening work groups to deliberate the intent of the new legislative language and to articulate concepts, definitions, and federal policy;
- Convening forums to increase awareness of elected state officials and policymakers regarding child health needs, related MCH program mandates, and opportunities to enhance state action to address these issues; and
- Providing funds to academic centers and other nonprofit organizations to further this work in support of nascent state efforts through materials development and technical assistance.

As an extension of several collaborative initiatives with MCHB to articulate "primary care" and to develop methods and tools for measuring it, the Child and Adolescent Health Policy Center at The Johns Hopkins University joined with the Maternal and Child Health Bureau and the National Center for Education in Maternal and Child Health in April 1994 to convene the workshop, Assessing and Developing Primary Care for Children and Youth. Co-chaired by Dr. David Heppel, Maternal and Child Health Bureau, and by Dr. Bernard Guyer and Dr. Barbara Starfield, The Johns Hopkins University, the workshop provided a forum for critical thinking and analysis related to concepts and models for configuring, under health care reform, a primary health care system for children and youth. The purpose of the forum was to consider public and private sector roles, and the resources and support needed to implement effective systems of care at the community level for children and their families.

A group of approximately 50 researchers, child health policy experts, and public and private MCH practitioners and policymakers were invited to participate in the two-day forum held April 20–21, 1994, in Baltimore, Maryland. Appendix B provides detailed information about the participants, who represented a wide range of national organizations, individual states, the Institute of Medicine, and federal health agencies and programs in addition to the Maternal and Child Health Bureau.

The objectives of the workshop were to:

- Articulate the parameters of primary health care systems;
- Explore methodologies for assessing primary health care systems for children and adolescents;
- Explore elements of and methodologies for developing community capacities for systems planning, implementation, and evaluation;
- Articulate the concepts of "accountability" and its measurement in systems development; and
- Discuss the implications of primary health care systems development for state and local public MCH program capacities.

To facilitate full discussion among participants, papers addressing these topics were prepared and shared in advance of the workshop, and selected participants served as respondents and discussion leaders. Discussion throughout the two-day forum was rich and provocative, as participants challenged commonly held notions and debated opportunities for advancing an appropriate national response to child health systems needs.

Although neither the purpose nor the outcome of the workshop included consensus development, several recurring themes emerged from the presentations and discussions:

- Poor child health status and health services delivery issues indicate that the system is broken—communication and coordination as well as new partnerships are needed to make a workable system;
- A conceptual framework for organizing and assessing the health services system can be used to guide assessment and program development strategies and tools;
- Public health roles are essential in order to address child health population needs;
- Public–private partnership models are evolving;
- New challenges, roles, and models require attention to systems capacity issues; and

- A new vision and societal commitment are needed to effect positive child health status and systems changes.

These themes are discussed in the Overview in this publication, within the context of both the individual papers and the workshop deliberations. Dr. Bernard Guyer's Commentary and Closure on the workshop follows the individual papers in this volume.

The Johns Hopkins University Child and Adolescent Health Policy Center and the National Center for Education in Maternal and Child Health prepared this compendium of the workshop papers as a resource for states, especially as health care debates and reforms continue to evolve at the state level. We hope this publication is helpful to MCH programs as they continue to provide public health leadership and advocacy on behalf of this nation's children and families.

Bernard Guyer, M.D., M.P.H.
Barbara Starfield, M.D., M.P.H.
David Heppel, M.D.
Holly Grason, M.A.
Rochelle Mayer, Ed.D.

October 1995

Contributors

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Deborah Klein Walker, Ed.D., is Assistant Commissioner, Bureau of Family and Community Health, Massachusetts Department of Public Health, Boston, Massachusetts.

Martin Wasserman, M.D., J.D., was Director of the Prince George's County Health Department in Maryland at the time of the workshop. Dr. Wasserman is currently Secretary of the Maryland Department of Health and Mental Hygiene, Baltimore, Maryland.

Overview

Several distinct themes resonated throughout the presentations and discussions at the April 1994 workshop, "Assessing and Developing Primary Care for Children: Reforms in Health Systems." These themes, which provide the framework for this overview of the workshop, concern the challenges of reforming health systems and the opportunities for organization and delivery of child health services:

- Poor health status of our nation's children and issues in delivery of health services indicate that the "system" is broken—communication, coordination, and new partnerships are needed to make a workable system;
- A conceptual framework for organizing and assessing the health services system can be used to guide strategies and tools for program assessment and development;
- Public health roles are essential in order to address the health needs of child and adolescent populations;
- Public-private partnership models are evolving;
- New challenges, roles, and models require attention to issues of systems capacity; and
- A new vision and societal commitment are needed to effect positive child health status and systems changes.

THE SYSTEM IS BROKEN

Opening remarks by ***David Heppel***, Maternal and Child Health Bureau, underscored some of the ways our nation is failing to meet the needs of children. In his presentation "Defining the Issues and Planning for Change," Heppel cites the prevalence of child homelessness, child homicide (the fourth leading cause of death in children), and alarmingly high rates of child poverty and hunger as clear signals demanding national action. Other workshop presenters and participants also voiced these

concerns, noting new stresses on health care providers, runaway medical inflation, maldistribution of resources, and a "disconnect" between medical care and public health.

Challenging a system of care that clearly is failing our children and youth, Heppel calls workshop participants to the vision and goals of primary care advanced by the Maternal and Child Health Bureau:

> *Primary care for children and adolescents is a personal health care service delivered in the context of family and community. Primary care is comprehensive in scope and includes services that preserve health, prevent disease and dysfunction, and care for common illnesses and disabilities. Primary care serves as the usual entry point to the personal health care system. It shares with the family of the child or adolescent ongoing responsibility for health care, whether illness or injury is present or absent. The primary care provider serves as the integrator of health services by furnishing most health care and counseling and coordinating needed specialty and supportive services. Finally, primary care includes mechanisms that assure the appropriateness, cultural acceptability, and quality of services being provided.*

This definition of primary health care for children and adolescents manifests the following attributes: community orientation, family-centered services, "first contact," ongoing responsibility, integration of services, comprehensive services, appropriateness and cultural acceptability, and quality. To achieve these standards for primary care, Heppel urges strengthening the infrastructure for publicly accountable child health service systems built through public and private partnerships.

Bernard Guyer's presentation reiterated the themes regarding current inadequacies in the delivery of health services for children, observing that "the system is broken." In their paper "Health Care Systems and Primary Care for Children and Adolescents," ***Bernard Guyer, Mona Shediac, Charlyn Cassady,*** and ***Holly Grason*** cite the definition of a "system" as "a set of interconnected, interdependent components that form a complex whole." A system has three essential elements:

1. A system has a purpose or goals;
2. A system has components—structures and processes that are differentiated; and
3. The components must communicate to be coordinated.

"Even if there are existing agencies, services, and individuals that provide care to members of a community, the collection of the parts will form a system only if each of the parts is compatible with the remainder and serves to maintain the equilibrium of the whole." When people say the system does not work, Guyer continues, this usually means that a system does not exist.

Guyer and colleagues cite the nationwide telecommunications system as a metaphor for understanding well-known systems that are in place in the United States, and describe health care systems for perinatal care and trauma care as representative of systems successes.

In their paper, Guyer and colleagues also present a framework for understanding the functional aspects of systems, based on Barbara Starfield's model, The Health Services System. The functional components of this model include *structural elements* (inputs or health resources), *process elements* (intermediate outputs or health services), and *outcomes*, as well as population and environmental (contextual) areas. Measuring these elements alone, however, will not allow complete assessment of the system. The nature of the communication and information processes at the core of a coordinated system also must be understood and scrutinized to determine whether a system can—and does—work toward achieving its objective.

PRIMARY CARE AS A CONCEPTUAL MODEL FOR RETHINKING AND ASSESSING THE SYSTEM

In her paper "Assessing the Status of Primary Care Services," ***Barbara Starfield*** notes that, in the United States (in contrast to other countries), primary care is *not* the cornerstone of the health care system. Major provider organizations in this country have only recently agreed on a common definition of primary care. Starfield summarizes the empirical evidence of the benefits of primary care, including lower mortality rates, well-controlled chronic conditions, and increased satisfaction with health services. She observes that the system of medical education has contributed to an inadequate primary care structure nationwide.

Starfield's paper defines and describes the "unique" attributes of primary care—*continuity (longitudinality), comprehensiveness, coordination,* and *first-contact care.* She further details "derivative" features—*community-oriented* and *family-centered* aspects, as well as the "essential" feature of *cultural competence.* Starfield's health systems framework presents primary care as an *approach* to care, rather than a set of services delivered by a specific medical care provider. The framework allows independent assessment of *structural* aspects such as defining the eligible population, accessibility, and governance; and *process* elements, such as problem recognition, diagnosis, disease management, utilization, and satisfaction. This framework also can measure behavioral (or process) features related to patterns of utilization, as well as the extent to which providers recognize problems experienced by patients and existing in the community at large.

Using the Starfield model defining the attributes of primary care and the health services system, ***Charlyn Cassady*** described the approach being developed at The Johns Hopkins University Child and Adolescent Health Policy Center (CAHPC) for assessing primary care provided to children. While some large data sets can be used to demonstrate certain broad-scale needs of specific populations, special surveys used as adjuncts to these large data sets can increase the specificity, validity, and reliability of information used for planning and resource allocation decisions, and for monitoring quality of care.

Cassady's paper, "Assessing the Status of Primary Care Services," presents CAHPC's initial experience in working with assessment tools to measure primary care at four levels: state or agency, community, facility or provider, and consumer. Cassady reviews the approach and the cautions related to each. Several tools are being developed—including surveys and a Community Self-Assessment Guide—to assess the provision of primary care specifically to children and adolescents; these tools are described in their specific applications in five states and the District of Columbia. Early pilot testing showed a fragmentation of services in two states, and provided the foundation for a framework for developing strategies to improve the current health system in two other states. Cassady notes that the experiences gained in these states, in particular, have been "instructive in showing how political jurisdictions can systematically address the important issues in planning for primary care services."

Workshop discussions turned time and again to measurement of primary care, especially systems of care, and to the critical need for a *population-oriented perspective* to assess reforms in financing and service delivery. Participants agreed that it is imperative to strengthen significantly the capacity for data functions within public health and to share public health expertise with the private sector.

Echoing this consensus, ***Deborah Klein Walker*** cautioned that "unless a basic maternal and child health population-based system is developed and operates at all levels of government, it will be difficult to assess child health status and monitor the impact of health care systems in the future." In her paper "Developing Population-Based Data Sets at National, State, and Local Levels," Walker states that the design, implementation, and monitoring of community-based, consumer-oriented, culturally competent primary care systems for children, adolescents, and their families rest on the availability of population-based data systems. Data must be standardized for use across agencies, not based on categorical program funding and reporting needs. Guidelines for developing integrated data sets need to be established and must contain appropriate data sources to facilitate needs assessments and evaluations at the community level as well as state and federal levels.

In her paper, Deborah Walker identifies the potential uses of information generated from an integrated population-based system and the criteria for standardization. A core data set, at minimum, should include four major categories of information: health status measures, service utilization indicators or process measures, sociodemographic and environmental measures, and behavioral risk indicators. "The consumer health 'report card' of the future should include information on patient outcomes in various ambulatory and inpatient settings as well as the health status of the entire community." Walker illustrates the possibilities of developing such data systems at the state level through experiences of the Massachusetts Community Health Information System (MassCHIP). MassCHIP incorporates "a wide array of state and community-level data into a single comprehensive database system" (census, vital records, hospital discharge, risk factor surveillance, disease registry, program data). Walker notes that the real potential of MassCHIP as a model that can be used to carry out core public health data functions for all maternal and child health care can be achieved only when outcome data are included for the entire primary care system.

In their paper "Assessing Needs and Monitoring Progress in the Delivery of Primary Care Services for Children and Youth," ***David Stevens, Rita Goodman,*** and ***Norma Campbell*** address the topic of population-based data systems for assessing and monitoring primary care from the perspective of Community and Migrant Health Centers (C/MHCs). Guidelines for developing high-quality, successful community health centers, developed by clinical and administrative staff from the Bureau of Primary Health Care and C/MHC representatives, are outlined in the document *Program Expectations for Community and Migrant Health Centers.* These guidelines specifically require the following components to be included in C/MHC needs assessments: (1) a definition of the service area and target population; (2) needs of the user population; (3) needs of migrant and seasonal farmworkers; (4) special population needs with respect to geographic, economic, cultural, and language barriers; and (5) identification of available public and private resources.

Stevens, Goodman, and Campbell also describe a Clinical Measures Tool developed by the Bureau of Primary Health Care. This instrument, constructed around a set of measures that reflect *Healthy People 2000* objectives, focuses on process and intermediate outcome measures and supports assessment of critical primary care interventions. Using a life cycle approach, the Clinical Measures Tool was developed to be acceptable to clinicians and communities, to be measurable and realistic, and to complement other national data initiatives.

Charles Danielson, Mary Anderson, and ***Kay Leeper*** discuss child health planning and assessment in Iowa's Office of Maternal and Child Health in their paper "Community System Assessment and Child Health Planning in Iowa." They present this issue through their experience gained in implementing the Healthy Foundations project funded by MCHB. Healthy Foundations works on a plan-do-study-act cycle with regard to the community as it identifies, analyzes, and promotes improvements in local systems of care. The project views community primary care enhancement as a partnership between the state and local sites, and emphasizes the importance of defining the community in order to identify those who will be influenced by an intervention. *Community,* as defined by the authors, is based more on functional capacity and patterns than on population size, geography, or governmental organization.

In the Healthy Foundations model, community coalitions are the keystones of local activity, whereby the local public health agency and core leadership of the community coalition identify local resource contributions and provide assurances to carry out the Healthy Foundations prototype. Each coalition is responsible for comprehensive assessment of its local primary care system for children. State-level support facilitates this process by providing training materials and demographic and health status data to the community. The state also provides matching funds and physician education forums, and has developed assessment tools for use by participating communities. The Iowa MCH program has found that using the *improvement framework* rather than a problems approach is more effective, since it focuses not on individual health status problems but on the *system*—emphasizing building on what works and making it better.

Lucille Rosenbluth's paper, "Evaluating the Delivery of Pediatric Primary Care in New York City," reports on the experience gained in evaluating Pediatric Resource Centers (PRCs), a pediatric primary care program targeting high-risk children. The service delivery model includes six components: availability, accountability, accessibility, continuity, comprehensiveness, and coordination. A two-tiered approach was developed to assess PRC performance: a process evaluation to confirm the existence of the model, and an outcome study to determine whether the model actually makes a difference in the health and well-being of those receiving services. Currently, the programs are evaluated annually through the review and analysis of project data collected from (1) a computerized data reporting system, (2) site visits, (3) chart reviews, and (4) quarterly fiscal reports.

Variables used to assess outcomes were grouped into seven categories: physical, psychosocial, and functional health; preventive health behaviors; health knowledge and practices; utilization of health services; and unmet needs for care. Results show that PRC children were less likely to be delayed in receiving immunizations, less likely to report health problems, and more likely to have received services through the Special Supplemental Nutrition Program for Women, Infants and Children (WIC). Five of the seven outcome categories appear to have been most affected by the PRCs: physical health, preventive health behaviors, unmet needs for care, health knowledge and practices, and functional health.

Overall, this evaluation has provided relevant and useful data for future program planning. Rosenbluth notes that "the importance of provider involvement in the development of methodologies, timely analysis, and feedback to field personnel, and the willingness to reassess and revise approaches as needed cannot be underestimated." Further refinement and possible replication of the evaluation model in different settings is the next challenge.

The question of the appropriate role of public health agencies in design and oversight of managed care health plan data systems also stimulated vigorous debate in workshop discussions. Public health needs to be able to access data collected in the private sector in order to effectively monitor community health status; participants expressed concern about the current tendency of managed care organizations and other insurers to keep this information out of the reach of government agencies. Debate also focused on the question of whether public health entities should collect and analyze all health services data directly, or whether the more appropriate approach is for government to set and enforce standards for private sector data collection, analysis, and reporting.

PUBLIC HEALTH ROLES ARE NEEDED

In their presentations on the roles of public health, David Smith, Martin Wasserman, and other discussants identified roles uniquely suited to either the private or public sector, as well as those that should be shared.

The keynote presentation by Texas Health Officer ***David Smith*** set the stage for the ensuing presentations and discussions on the infrastructure and accountability necessary to enable the health system to operate with coherence, compatibility, and, ultimately, effectiveness. In his paper "Delineating Public Roles in Planning, Providing, and Evaluating Primary Care Services for Children and Their Families," Smith provides historical context for the current environment of runaway medical inflation, maldistribution of resources, and impoverished health status in many sectors. Overattention to financing in health care reform is linked in etiology to "medical involution," characterized by an overemphasis on

tertiary care. Smith calls for "front loading" our health care investments with a renewed and strengthened focus on preventive services and on the practice of community-oriented primary care.

Building on the material in his paper, Smith's presentation described infrastructure needs and approaches as well as roles for public health in pursuing this new venue. These include:

- Providing nontraditional care in nontraditional settings;
- Encouraging flexibility in both dollars and data;
- Developing population-based eligibility strategies;
- Using marketing and incentives to promote new systems thinking and new health-promoting behaviors; and
- Realigning relationships among community-based health practitioners, tertiary medical institutions, and academic institutions.

Smith highlighted key public health roles in putting these pieces together—defining and prioritizing health problems, developing marketing and media initiatives, leveraging and brokering financial and human resources, and monitoring and being accountable for population health.

The critical role of local public health agencies in assuring community prevention strategies also provided the focal point for ***Martin Wasserman's*** paper "Public Health and Health Care Reform: Healthy People in Healthy Communities." Although echoing many of the themes outlined by David Smith, Wasserman specifically highlights public health responsibilities and strategies for assuring equity in health across populations through cultural competence, quality monitoring, and development of a shared vision of "healthy people living in healthy communities." While prevention (a traditional public health venue) increasingly is brought into clinical practice and supported through changes in insurance reimbursement, and the use of primary care gatekeepers is increasing, a significant "disconnect" remains between medical care and public health with respect to the needed focus on community health. Wasserman believes "we must fully integrate public and private health care into a prevention-oriented managed primary care and community-based protective system." To accomplish

this, a fourth component—improvement of health status for the family and community as well as for the individual—must be added to the national reform objectives of universal access, cost containment, and quality.

Wasserman reviews the components of the "Blueprint for Local Health Departments" (developed by the National Association of County Health Officials and the Centers for Disease Control and Prevention), which envisions a system centered on keeping people and communities healthy. Fundamental to this blueprint is government responsibility for controlling disease, reducing environmental hazards, providing health information and education, monitoring quality, and providing "safety net" health care and wraparound enhanced services for those at particularly high risk or belonging to hard-to-reach populations. Government roles also include public health policy grounded in science and supported by adequate data and surveillance systems. Investment in developing the cultural as well as technical competence of the health care work force; research, discovery, and innovation; and development of linkages between schools of public health and government agencies are key to meeting the challenges of the future. The most critical element, asserts Wasserman, is the need for authorities and funding to guarantee a local government health presence with the ability to regulate, facilitate, and evaluate health care services to assure a holistic system of care.

From the perspective of the private pediatric practitioner, Susan Aronson noted that public health authorities should be charged with the role of "organizing systematic approaches" to serve stressed and vulnerable families. She further called for public health to include specific functions: providing a pool of resource professionals that can be accessed by private providers for referrals for care coordination, home visiting, and other enhanced health services not efficiently implemented in individual practices; organizing regional networks of specialty care; and administering community-wide programs for environmental health, nutrition, and prevention and education.

In the paper "Accountability in Primary Health Care Systems," ***Bernard Guyer, Mona Shediac,*** and ***Holly Grason*** discuss the divergent views of accountability stemming from differing political orientations. They note the fiscal focus many groups assign to "accountability" in debating health care

reform. Alongside these cost containment notions of accountability is the public health community's quite different emphasis on accountability for the health and well-being of the population. The complexities of "accountability" are examined, drawing from Lester Salamon's framework analyzing the distinct tools of government action available within government's current operating environment, by indirect or "remote" control. The authors outline these concepts, as well as a framework for documenting public accountability through a model of service efforts and accomplishments, in the context of ensuring accountability for immunizing children. Guyer and colleagues further discuss how current notions of shared responsibility are implemented through the use of incentives.

Issues of accountability generated vigorous discussion during the course of the workshop. Participants agreed that a major challenge facing accountability for primary care for child and adolescent populations is the lack of national consensus on societal responsibility for assuring the health of the population. A strong rationale must be developed for assigning public health agencies the societal responsibility for this accountability.

PUBLIC-PRIVATE PARTNERSHIP MODELS ARE EVOLVING

Several presentations and substantial discussion focused on strategies for assessing and developing primary care systems in a changing health care environment. Key issues concern (1) the organization of medical and nonmedical health services in communities, and (2) local and state public health agency roles in building community capacity and supporting public-private partnerships. Workshop presentations and deliberations highlighted the fact that innovations are already occurring on their own—absent a national reform template.

In her paper "CHIP—A Community Model for a Comprehensive Health Care System," ***Peggy Balla*** discusses the organization of services in communities, based on experiences with the Child Health Investment Partnership (CHIP) in Roanoke, Virginia. The CHIP emphasizes comprehensiveness, coordination, and continuity of care. Through CHIP, the medical home is provided by private practitioners

who enter into agreements with the public health agency, which coordinates care, assures appropriate use of health services, and provides or arranges linkages for enhanced services. Care coordination is provided by public health nurses who prepare a comprehensive health care plan for each child. There is a single point of entry, and referrals are made to an integrated network of services.

The framework developed for assuring the community's capacity to implement the CHIP model includes building interorganizational public-private partnerships, developing and maintaining a responsiveness to local needs, and combining and finding new funding sources. Balla describes elements of implementation success as (1) community involvement, (2) needs assessment, (3) single point of entry, (4) public health department wraparound services and tracking, and (5) blended funding.

Public-private partnerships are the cornerstone of CHIP. This means the willingness of partners to collaborate and share resources, to create a shared vision, and to share in the solutions and successes. It also includes the presence of leadership. "Partners" should be selected based on their power and authority to effect change and open doors in the community. In addition, knowledge of resources available in the community, willingness to provide a long-term commitment, autonomy in data capacity and support, and flexible and creative financing are fundamental to the model. The model also includes working together to integrate health and social services, paying particular attention to social contributors to poor health.

In his paper "Primary Care Provider and System Challenges in Caring for High-Risk Children and Families," ***Larry Culpepper*** discusses linking traditional practice with public health services. He stresses the importance of establishing a medical home in the private sector with additional services (such as those required by high-risk individuals and their families) provided through partnerships with public health services. Because high-risk children and youth require different levels of support, adequate nonmedical resources must be built into the private medical practice to enable the primary care system to respond to their needs. Such resources should include transportation, translation, and child care services, as well as specialized medical, educational, and social services for children with developmental disabilities or chronic illness, and for families experiencing other dysfunctions.

Culpepper identifies three basic models for private physician involvement with high-risk children and youth. The "linked traditional practice" is a traditional solo or group private practice in which providers refer patients to another entity that "assumes coordinating responsibility and possibly provides some or all nonmedical components." The "activated practice" differs in that the primary care practice assumes greater (though not necessarily complete) responsibility for the high-risk family. The physician or other clinician may assume some case management responsibilities for initial assessment and ongoing care coordination. This model also may involve on-site or closely linked services provided by social workers, nutritionists, mental health counselors, or other professionals. The "fully activated practice" assumes leadership responsibility for developing a system of care within the community for high-risk children and youth. This will generally require an on-site professional team skilled in providing various services required by the high-risk population being served. This third model is similar to a fully functional community-oriented primary care practice—the primary responsibility for care coordination is assumed by the practice. It is possible that, over time, practices could progress from the first to the third model.

Jane Pearson's paper, "Pediatric Primary Care Systems Development Initiatives in Arizona," presents Arizona's experiences in building a primary health care system for children where a statewide task force has provided the backbone for primary care systems development. The task force determined the need to develop a common definition of a primary care system, and later found it necessary to become proficient in marketing and community development in order to implement the prototype it developed.

The task force (1) helped outline a "blueprint" for a primary care system that can be customized by communities, depending on the population's needs; (2) effectively increased community development efforts, viewing communities as "our best resource for effecting system change"; and (3) developed a variety of service delivery options to enhance community capacity to assure that all women and children have access to and use primary care services. Public-private partnership program models include a "medical home" program, "Passport" program (medical record tracking system for parents of newborns), school health clinics linked with guidance centers and hospitals, and training and

technical assistance from the state to individual communities. Concepts and "gold standards" for providing primary care have been integrated into virtually all programs within Arizona's Office of Women's and Children's Health, through formulating statewide policies and program strategies that assure and support implementation.

In his paper "Health Care Reform and Public Health Considerations in Alabama," ***Larry Menefee*** describes transition issues facing the Alabama Department of Public Health (ADPH) in shifting from a significant focus on direct provision of health services, as health care reform is realized. The principal themes involve the questions of how to transform the current two-tiered system of health care into a system providing significantly stronger primary care services and necessary access, and how to transform the activities of ADPH to complement and support the reformed health care system.

Three models or prototypes could accomplish the transition of personal health services currently provided through ADPH: (1) the entirely public model, (2) the public-private model, and (3) the privatization model. The public model, requiring additional investments in the public service structure, is not seen as financially or politically feasible in the current reform environment. Under a public-private model, joint operating agreements would be established in order to continue or enhance current services without additional cost. ADPH could continue to provide direct care, with individual clinics becoming integral parts of a primary care system. This public-private model would provide the opportunity to assure continuity of care at the public health facilities. In the privatization model, ADPH would no longer provide direct personal care, but would enter into agreements with other area providers (and possibly sell ADPH facilities, requiring the buyers to provide primary care for a period of time).

The decision facing ADPH is whether to continue providing personal care services or to relinquish this role to other entities and take on new functions. This raises additional questions about what the new functions should be, whether they are best handled by state health agencies, and, if so, what arguments are needed to develop consensus.

NEW ROLES AND MODELS REQUIRE BUILDING SYSTEMS CAPACITY

Maxine Hayes and several other authors addressed the question: What is needed to move forward to develop an integrated public-private system grounded in partnerships and government accountability for population health? Using Starfield's Health Services System model as the framework for her remarks, Hayes outlined the state agency perspective on the structures, processes, and outcomes central to accomplishing the mission of promoting and protecting the health of women and children.

In her paper, "What's Needed to Move Forward? State MCH Program Perspectives," Hayes notes that new organizational structures are needed within public health agencies to promote "systems thinking" and the integration of activities across programs and populations. She foresees a major shift away from concentration on direct service delivery to the execution of core public health functions. "Beginning with a new way of organizing our human and fiscal resources," states Hayes, "MCH will have to retool staff for new roles, while deploying others who are uncomfortable with change, to the private sector." In the state of Washington, numerous smaller, categorical units have been folded into a new structure having three major units for (1) all policy functions, (2) all data functions, and (3) all personal health services. Hayes also cites the need to develop public health agency personnel skills in marketing, technical assistance to communities, effective communication, facilitation, negotiation, and community mobilization.

With respect to process, Hayes emphasizes the need to institute agency practices for identifying, defining, and monitoring health problems impacting entire communities. Hayes also says that "our 'process' thinking must center on interventions that focus on changing behaviors if we are to impact health status." Adequate capacity also must be developed to evaluate intervention outcomes over time, and epidemiologic methods need to be applied across programs and disciplines to track health status.

New capacities are indicated for the private sector as well. In workshop discussions, Larry Culpepper noted a number of provider issues that must be addressed if the linked comprehensive approaches

are to be implemented to any significant degree systemwide. Increased data and patient care management capacity and an expanded model of care and ongoing doctor-patient relationships are likely to be required. A new common definition of primary care providers must also be established; such changes in practice will best be accomplished if guided by health services research and supported by changes in the professional education of physicians and other helping professionals. For this to occur, Culpepper believes there must be expanded curriculum, community-oriented teaching environments ("the Community ICU"), and education-based research. Thus, closer scrutiny of the content and process of medical education is needed as the private sector becomes responsible for serving larger caseloads of low-income and other vulnerable family populations.

Susan Aronson's paper, "Meeting the Contemporary Needs of Children and Youth with Developing Primary Care Systems," describes the *Bright Futures* guidelines as the backdrop for discussion of the challenges faced by the private sector in caring for a larger proportion of high-risk and special needs subpopulations, noting that practitioners must accommodate to the needs, expectations, and behaviors of these groups. Of major importance are additional time and flexibility in practice routines in order to respond to needs, and adjustments to provider compensation for both in-office care and care coordination, and for participating in community services planning and coordination initiatives.

Aronson also calls for application of new technologies to reduce the paperwork and management burdens of office-based providers, for the strategic use of incentives to change provider and consumer behavior, and for implementation of creative educational strategies to support the appropriate use of community services for the children receiving care. Aronson finds that with "special training on how to view and serve the community as another type of patient," much potential can be found in partnerships linking private sector health professionals and public health initiatives.

Aronson defines the essential system elements as (1) universal access to medical care, (2) community-wide environmental services, and (3) multisystem services to address complex issues impacting health, such as poverty and violence. Above all, Aronson asserts that what is needed to assure a seamless service continuum for children is "consensus on objectives of health services delivery."

A NEW VISION IS NEEDED

Bernard Guyer presented his Commentary and Closure by synthesizing the many lessons learned through the workshop. Using the three essential components of a system—shared goals, components that are differentiated and defined, and effective communication mechanisms—as the organizing framework for this discussion, Guyer concluded that value-based as well as data-based arguments, strong advocacy, creative experimentation, and sound evaluation are needed to ensure that emerging health care systems serve the needs of children and families.

The tasks of designing the roles of public MCH agencies in an era of organized, privately owned managed health care systems increasingly challenge the field, and will grow in importance in the future. Guyer noted that, ironically, the emerging managed care industry is already oriented toward using the systems language and management approaches in thinking about its own development—the task becomes to orient the public agencies to thinking in this manner.

The Title V legislation sets broad goals for child health in this country, and *Healthy People 2000* articulates these goals in specific, measurable objectives for health status and health care utilization. These national goal statements, which are population oriented and encompass all children and their families, must guide managed care organizations as well as public sector efforts.

The components of an effective primary care system, coupled with implementation of a child-specific standard of need, must be present if the system is to yield the kinds of positive outcomes that have been documented in many European countries. Primary care systems can be delivered from a variety of institutional bases and through a variety of creative arrangements coordinated between public and private sectors. Clearly, however, all children's health specialists must be involved in the development of such systems. The standard setting—regulatory and contractual authorities of public MCH agencies at the state and local levels—are the tools of government that should be used to build such a system.

Fundamental to systems theory is the notion that the components of a system communicate among each other to meet the common objective. At the basis of such communications are data systems. Current data development initiatives must be expanded to include the data elements necessary to assure that the system is working for the benefit of children.

Future development of the health care system will be driven by the major societal forces—including shifting demographics, further efforts to curb the growth of health care costs, and less dependence on regulatory mechanisms coupled with more dependence on the marketplace to guide services development. In this environment, advocates for children must make the case for the benefits of organized systems of primary care as the foundation for the adequate development and health of our children.

We would join with those observers who make the case for an investment strategy—we must invest in the health and development of our children if the nation is to have a strong and secure future.

Defining the Issues and Planning for Change

Health Care Systems, Primary Care, and Reform

I am pleased that you have gathered here to address the important issues of children, primary care, and the role of state and local health departments in ensuring delivery of primary health care within a comprehensive system of health care.

Let's talk about basic beliefs. Children are America's most important resource. How many times have you heard that cliché? But, like many cliches, it's true. Children *are* America in the next century. They will be the people providing your food, your shelter, making your life more pleasant . . . or unpleasant. They will be the decision makers, influencing their lives . . . and yours. As my friend Bill Hollinshead said: "To preserve, protect, and promote the health of children should be a high national goal, because it is right, and because it is wise." Our standard of living as we grow older will depend as much on how we care for and nurture our children as it will on how we individually prepare ourselves.

by
David Heppel, M.D.

During the 1990s and into the next century, our work force will be getting smaller. New additions, for the most part, will be women and children—all of our children.

- Our children, of whom one in five lives in poverty. Two-thirds of these children have a parent who works full-time.
- Our children, of whom more than 100,000 are homeless on any given night, representing the fastest growing group with no place to live.
- Our children, for whom homicide is now the fourth leading cause of death, except among adolescents, for whom it is the second leading cause of death. For black males, homicide is the leading cause of death.
- Our children, too many of whom don't have enough food to eat, don't have a place to stay, don't have a stable home life, don't feel safe, and, most important, don't have hope.

These are the people on whom all of us in this room will ultimately be dependent. Our responsibility should not be to assure that we have healthy infants or healthy preschoolers or healthy adolescents. Our responsibility should be to produce physically, emotionally, and educationally healthy, hopeful, and functional adults. . . because it is right and because it is wise.

DEFINITION OF PRIMARY CARE

Let's talk about primary care. There are many definitions of primary care; the Maternal and Child Health Bureau has adopted the following definition:

> *Primary care for children and adolescents is a personal health care service delivered in the context of family and community. Primary care is comprehensive in scope and includes services that preserve health, prevent disease and dysfunction, and care for common illnesses and disabilities. Primary care serves as the usual entry point to the*

personal health care system. It shares with the family of the child or adolescent ongoing responsibility for health care, whether illness or injury is present or absent. The primary care provider serves as the integrator of health services by furnishing most health care and counseling and coordinating needed specialty and supportive services. Finally, primary care includes mechanisms that assure the appropriateness, cultural acceptability, and quality of services being provided.

The definition of primary health care for children and adolescents incorporates eight attributes:

- Community orientation
- Family-centered services
- First contact
- Ongoing responsibility
- Integration of services
- Comprehensive services
- Appropriateness and cultural acceptability
- Quality

Primary care for children and adolescents means caring for individuals in the context of the community from which they come. It means having both epidemiologic awareness and knowledge about effective community and environmental interventions. Primary care serves as the bridge between medical care and public health by incorporating a population-based perspective into daily clinical practice to facilitate community diagnosis, health surveillance, monitoring, and evaluation.

Primary care means services provided with an awareness of the family as a major participant in the assessment and treatment of a child or adolescent. The family is the largest determinant of how health services are sought and used. Primary care for children recognizes that since the family is the unit of living in society, the family is also the unit of health and illness. As such, families have the right and duty to participate individually and collectively in planning and implementing their health care.

Primary care means that, as first contact, it is the entry point to the personal health care services system. First contact goes beyond interactions at the provider site and includes outreach specially targeted to categories of children and youth at high risk.

Primary care means assuming ongoing responsibility for the child, regardless of the presence or absence of disease. This responsibility of providing a "health care home" for the child or adolescent implies accountability for the availability and quality of services. Primary care is a personal health care service. It focuses on the health needs of individuals and families. It involves a unique interaction and communication between the patient and the provider. In that sense, it is not only personal but personalized health care.

Primary care means that when other health resources are involved, the primary care provider has the responsibility of transferring information to and from those other resources, participating in the coordination of treatment plans, and managing the physical, psychological, and social aspects of patient care as capably as possible. This responsibility requires that the child or youth be seen holistically, that the fragmented perspective of the specialists be put into a human perspective.

Primary care means providing services that preserve health, prevent disease, and care for the common illnesses and disabilities of children and adolescents. Preventive and most curative services are provided by the same provider or team of providers. These services include clinical/technical interventions and related auxiliary services; human support ranging from managing most psychosocial problems to helping children, adolescents, and their families cope with life's exigencies; patient education; and facilitative services (i.e., services that enable the delivery of all other needed services such as transportation, translation, child care, and eligibility services).

Primary care services means providing services that take into account the developmental and cultural differences of the children and adolescents being served. Services should be acceptable to groups of people within the community being served who share common values, languages, world views, heritages, institutions, or beliefs about health and disease.

Primary care means having mechanisms in place to assure that the range of services and professional skills address the major health problems of the community's children and adolescents; and that those services are delivered in accordance with professional standards.

We in the Maternal and Child Health Bureau are committed to assist states and localities to develop such systems of primary care.

Now, let me tell you what primary care is not. It is not sexy; it is not glamorous; it does not get space on the front page of *The New York Times*, *The Washington Post*, *The Des Moines Register*, *The Albuquerque Journal*, or *The Arizona Republic*. It is not particularly exciting to the public. And (not surprisingly), it is not exciting to political leaders. Unfortunately, however, a functional primary care system is the cornerstone of our efforts to maintain a healthy society. It is our basic personal health infrastructure. We may not be aware of the primary care system when it is functional, but we are certainly aware of it when it fails.

In 1989, my viewing of the World Series was interrupted by nature. The Bay Area earthquake and aftermath had all of America riveted to its televisions. Two pictures stand out in my memory—the car going into the hole in the Bay Bridge and the rescue workers attempting to find people in the wreckage of the collapsed Nimitz Freeway. Sometime later I was reading about this freeway. If you recall, not all of it collapsed. It seems that in the late 1950s, a program was begun to reinforce the supports of the freeway. In the early 1960s, money was shifted to other more apparent problems before the project was completed. Until that day in October 1989, it made no difference. On that day, it made a critical difference. . . . Infrastructure. Do the recent events in Los Angeles, particularly regarding the freeways, sound similar?

My brother, who is a lawyer for Paramount Pictures, tells me that it costs $35 million to open the gates—no movie stars, no directors, no movies. Yet, Paramount couldn't exist without that $35 million investment . . . . Infrastructure.

Today, we hear about the problems of vaccine-preventable illnesses. Measles, which should no longer exist, is on the rise. We have responded with a number of efforts to improve the vaccine delivery system. Care for children with HIV is a major problem today. We have difficulty in providing appropriate prenatal care. I submit that a truly comprehensive, family-centered, community-based system of care would provide us with a foundation upon which to build an effective programmatic response. And without such a foundation, any programmatic responses we do make will be, at the worst, ineffective, and at the best, excessively costly.

While adequate health care does not equate with maintaining good health status, lack of health care is a significant contributing factor to poor health status.

While adequate health care does not equate with maintaining good health status, lack of health care is a significant contributing factor to poor health status. We deserve a health care system that meets our needs and we should accept the responsibility for devoting the energy and resources necessary to produce such a system.

How do state and local health departments fit into this picture? I see the role of the health department defined in terms of the three categories described in the Institute of Medicine's document, *The Future of Public Health:* assessment, policy development, and assurance. Health departments are directly responsible for maintaining the infrastructure of the nation's health system, i.e., both for population-based interventions like putting up a guard rail or fluoridating a water supply, and individual health care services such as primary care.

Who is responsible for individual health care for kids? If you ask pediatricians, they are likely to tell you that they are responsible. If you ask a community health center, you are likely to hear that it is responsible. If you ask some health maintenance organizations, you may hear them claim the responsibility. Many organizations are involved in providing health care for children. I believe the answer to this question is "all of the above." But if you ask who is ultimately responsible—where does the buck stop?—my answer is that the buck stops with the health department. Someone must take the broad view, someone must represent the community. It is wonderful that health departments provide ser-

vices to our neediest citizens, but it is not enough. Someone must be the synthesizer, someone must take the lead. Someone must be able to identify the missing or misaligned pieces in the comm[illegible]nity health care puzzle. I believe that someone is the health department. Others can provide direct health care services. Only the health department can play the integrating role.

A "TELLING" STORY

In Holyoke, Massachusetts, there is a private obstetrician who donates time to work at the local health department clinic. He is pleased to help and feels that the care he provides and the care provided by the nutritionists, social workers, and public health nurses is first-rate. He then goes back to his private practice where he sees women who are only marginally better off than those he saw at the clinic. But the system will not allow him to provide the enhanced care of the health department. No social workers, nutritionists, or public health nurses. It makes him feel that he is not providing as high a level of quality care to his own patients. It makes him think twice about donating time. Health is a community responsibility and should be available to the community as a whole—based on vulnerability, perhaps—but available to all.

In an ideal setting, I believe it would be best if health departments did not provide so many direct personal health care services, but, rather, concentrated on the difficult task of primary care systems development and supported those allegedly ancillary services such as home visiting, case management, and nutrition (which are unlikely to be fully supported in any health care reform, but without which we really cannot do a good job).

We have a perplexing puzzle of health care providers. Who can turn these pieces into a mosaic, a pluralistic system that works? Under present circumstances, that role belongs to government.

The goal of a functional primary care system for children (let alone for the rest of us) will not be achieved today or tomorrow or next week or next month. But it will never be achieved unless we

begin, unless we reach out to our fellow health providers, to our fellow human service providers, to our fellow citizens.

The efforts of this work group will help provide the perspective and the tools for us to move forward in a governmental and private partnership to develop a functional system of primary care that meets the needs of children and families. It is a difficult task for which we have not been fully supported, but it is an important task. We clearly have responsibilities far beyond our authority. But, if we do not accept this challenge, who will?

Health Care Systems and Primary Care for Children and Adolescents

Overview and Context

THE PERCEPTION OF A HEALTH CARE SYSTEM

There is a perception in this country that the health care system is "broken" and needs to be fixed. "There is no excuse for this kind of system . . ." stated President Bill Clinton when he introduced his health security legislation on September 22, 1993. "My fellow Americans, we must fix this system."[1] The headline in The New York Times the next morning read, "Clinton Asks Backing for Sweeping Change in the Health System."[2]

The purpose of this paper is to explore the concept of "system" in relation to health care delivery. We want to raise the following questions: What does the concept of system mean? Is it useful? How can we use a systems approach to health care to improve the health of women and children?

by

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Beginning with this paper, and continuing with the workshop presentation papers that follow, we hope to provide an overview of the concept of systems in health care and to show how the focus on systems of care can be important to improving primary and preventive care services for children.

WHAT IS A SYSTEM?

The concept of a system is well known and commonly used in our society. Systems-related terms and concepts have been used in management, engineering, health, science, and the social sciences. When people talk about a system of highways, for example, they mean a transportation network that functions as a unit. When biologists talk about the cardiovascular system, they refer to a group of body organs that are physiologically coordinated to perform a vital function. While the welfare system and the health care system may be complex, we should be able to understand their characteristics and processes in order to improve services delivery.

A system is defined as a set of parts coordinated to accomplish a set of goals.[1] In essence, a system is a set or group of interconnected, interdependent components that form a complex whole. Systems involve three essential elements:

1. A system has a purpose or goals;
2. A system has components—structures and processes that are differentiated; and
3. The components must communicate to be coordinated.

We propose in this paper to take a common sense approach, rather than a technical engineering approach, to understanding systems. Systems stress channels of communication, flow of information, and decision making. Systems are purposeful—that is, they select outcomes as well as means for achieving those outcomes. The central thread of any system is information and the flow of information between the various links of the communication network that supports the operation of the system.[1]

When people say the system does not work, this usually means that a system does not exist. Even if there are existing agencies, services, and individuals that provide care to members of a community, for example, the collection of the parts will form a system only if each of the parts is compatible with the remainder and serves to maintain the equilibrium of the whole. The essence of a systems approach is the focus on "systems taken as a whole, not on their parts taken separately."[4]

Example of the Telecommunications System

Before applying the concept of systems to health care, it might be illustrative to explore a system about which we all have common knowledge—the telecommunications system. The goal of this system is obvious, to allow communication between individuals all over the world by telephone. The structural components of the system are also well known, including the telephone receivers we have in our homes, our offices, and (increasingly) in our cars. The telephone poles, lines, microwave towers and other hardware components are familiar. There are practitioners, operators, who, even in the face of increasing automation, act as facilitators and gatekeepers. There are processes including simple one-to-one communication, long distance phone call , teleconferencing, and complex switching and rerouting operations; few of us understand how these processes work. Finally, the internal monitoring and feedback communication within this system is critical, and, therefore, supported by elaborate computer networks.

Other characteristics of the telecommunications system are relevant to our further discussions of health care. For one, not everyone has access to the system—an estimated 15 million Americans (6 percent of the population) have no telephones in their homes.[5] There are also financial access issues—not everyone can afford the same level of service and may be restricted to "basic" plans. There are multiple providers of telephone services—alliances and networks. The telecommunications system has addressed one aspect of a multiple providers and payers system, however, by providing a unified single billing statement. The business and financial complexity of this system rivals that of health care.

When the telephone isn't working, it could represent either a personal problem or a systems problem. For example, when a teenager drops the receiver and pieces fly out, that's a behavioral problem,

not a systems failure.[1] However, systems failures can occur, unrelated to user behavior, that represent either problems with hardware structures or software processes. Several years ago, for example, the long-distance switching in the entire Mid-Atlantic region shut down because of a computer programming error.

This telecommunications system analogy also lends itself to understanding the notion of assessing the system. The telecommunications industry is in the business of not only transmitting information but also monitoring the movement of that information. Again, the flow of information is the central thread of a system. For example, we can assess how well the telephone system is working by measuring consumer satisfaction, number of phone calls that get through, delays in connections, and other process measures.

Finally, the telecommunications system is regulated as a utility; that could be an instructive model for the health care system.

THE HEALTH CARE SYSTEM (OR NONSYSTEM)

The use of the term "system" in connection with health services is relatively new.[2] The nature, size, and complexity of the health field compels a systems approach to the management of health services.[3] For the most part, however, the discussion of the concept of systems in health care is more theoretical and ideological than it is real. In many cases, particularly in the primary and preventive health care settings, the elements of a system are missing; we have, in fact, a nonsystem of health care delivery. One major rationale for this workshop is to identify the elements of systems that can be applied to children's health care and begin to develop these.

Mandates for Systems in Maternal and Child Health

Since its enactment, Title V has aimed to "create a state capacity to develop systems of care for women and children, including handicapped children."[4] This objective was formally added to the

statute by the Omnibus Budget Reconciliation Act of 1989 (OBRA '89) amendments. For children with special health needs, the OBRA '89 amendments to Title V added the following:

> *to provide and to promote family-centered, community-based, coordinated care (including care coordination services, as defined in subsection (b)(3)) for children with special health care needs and to facilitate the development of* community-based systems of services *[emphasis added] for such children and their families.*[8]

Moreover, the *Healthy People 2000* objectives include development of systems for children (Objective 17.20):

> *Increase to 50 the number of states that have* service systems for children *[emphasis added] with or at risk of chronic and disabling conditions, as required by Public Law 101-239.*[9]

The Maternal and Child Health Bureau subsequently incorporated an expanded version of Objective 17.20 into the Maternal and Child Health (MCH) Block Grant application guidance:

> *All states will establish a statewide network of* comprehensive, community-based health care systems *[emphasis added] that serve women of reproductive age, infants, children, adolescents, and children with special health care needs; the systems will assure family-centered, culturally competent, coordinated services.*[10]

Furthermore, with regard to the specific provision of primary care services, Objective 6.14 of *Healthy People 2000* states:

> *Increase to at least 75 percent the proportion of providers of primary care for children who include assessment of cognitive, emotional, and parent-child functioning, with appropriate counseling, referral, and follow-up, in their clinical practices.*[9]

By meeting these objectives and carrying out the statutory responsibilities for system assessment and reporting, the Title V MCH Program provides leadership at local, state, and federal levels in

developing and auditing system response to the needs of women of reproductive age and the needs of children and youth.

Examples of Health Care Systems Successes—Regionalized Perinatal Care and Regional Trauma Systems

To make progress in applying systems concepts to primary health care, we need to demystify "systems." A good example of a well-known system in maternal and child health is the regionalized perinatal care system. It exemplifies the three essential parts of a system:

1. Its purpose is to improve the survival of neonates.
2. Its components are maternity/infant care units at different levels: Level 1 provides basic care to normal newborns; Level 2 provides a higher standard of care for newborns with some health conditions; and Level 3 provides the most intensive level of care to the sickest neonates.
3. The components of the system—Level 1; 2, and 3 units—communicate with each other concerning patients, and individuals are actually transported from one level to another according to their need for clinical services.

Another well-known health care system is the trauma system or emergency medical services (EMS) system. Again, our general knowledge of trauma and EMS care can be translated into the language of systems:

1. Its purpose is to improve the chances of survival for those suffering serious traumatic injury or sudden illness.
2. Its components include various levels of sophistication of specialized trauma care units and the mobile units that respond to injury events, stabilizing and treating injury victims at the scene, and preparing them for transport to the trauma units.
3. A sophisticated communication system links the levels of trauma care and mobile units, transmitting information needed to reduce response times in order to respond

to traumatic events, improve care at the scene of the event, plan for the care in the hospital, and monitor the progress and efficacy of that care. Access to the system, across the nation, begins by dialing 911.

Example of Health Care Systems Failure—Immunization

Unfortunately, the primary health care system for children in this country is not working to assure either adequate access to care or the attainment of health status objectives. The failure of this primary health care system has resulted in the low immunization levels among U.S. children. Immunization coverage can be understood in relation to the three components of a poorly functioning primary care system.

1. The goal of the primary health care system in relation to immunization services is defined by such expert groups as the American Academy of Pediatrics and the Advisory Committee on Immunization Practices. The recommended periodicity of preventive care visits and immunization antigens is well established and well known; nevertheless, primary care providers fail to set their own goals for immunization coverage.
2. The components of the primary care system are a variety of providers in public and private settings that offer immunization services. While the number of providers may be adequate, there may be problems of maldistribution in relation to certain populations and of lack of availability due to financial barriers. Further, the processes of clinical practice and office management may result in a failure to assess the immunization needs of individual patients, inappropriate deferral of immunizations, or missed opportunities for immunization.
3. Communications are, in all likelihood, at the heart of the failure to immunize U.S. children adequately. Primary care providers and public health agencies generally do not have systems for maintaining information about immunization of children at the level of the individual child, the facility, or the community. As a result, the sys-

tem fails to transmit critical information about upcoming or missed appointments to families and providers. In addition, primary care providers may not be properly informed about contraindications to immunizations, resulting in missed opportunities to vaccinate.

In this example, immunization is used as an outcome indicator of the functioning of the children's primary health care system. One of the challenges facing this workshop is to translate the concepts of systems in order to design and assess the effectiveness of systems of care that provide primary and preventive health services to children. Many of the papers address ways of assessing and improving these systems characteristics.

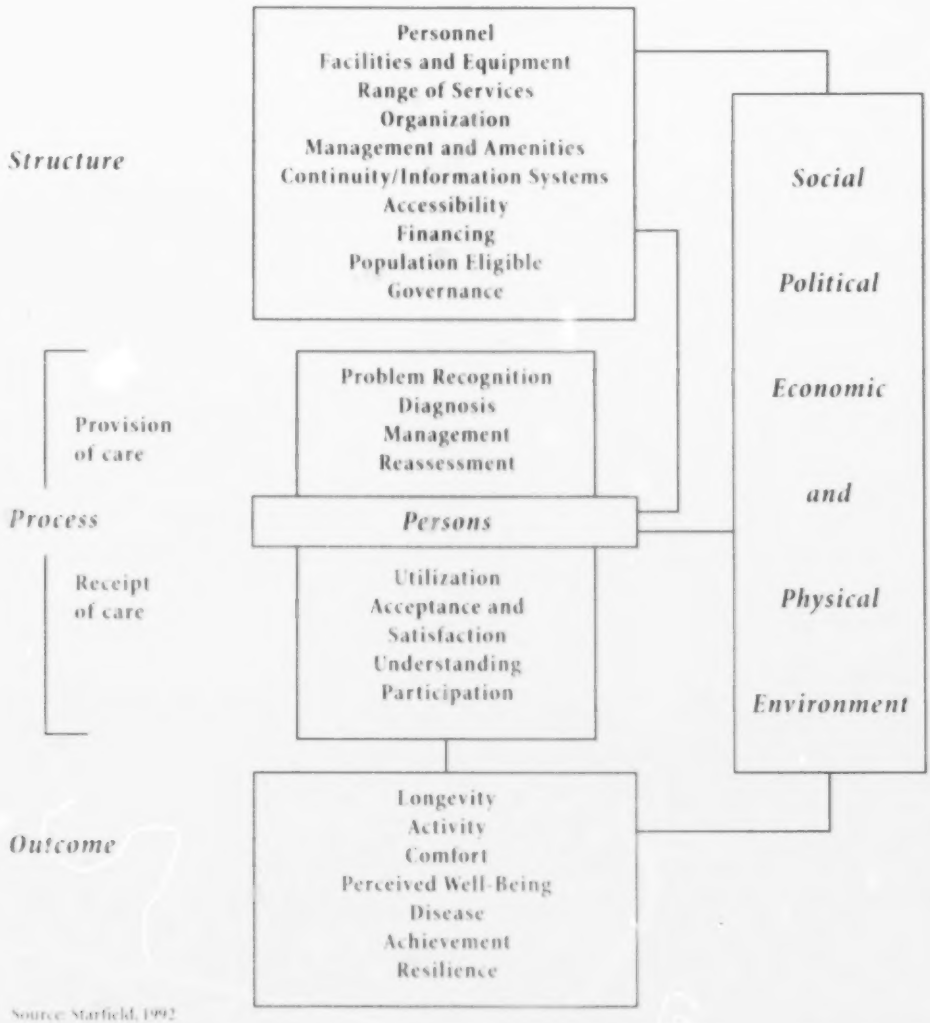
THE FUNCTIONAL ASPECTS OF THE HEALTH CARE SYSTEM

Systems of health care need to be understood, both by describing their components and the communications that exist between them (a mechanistic approach), and by understanding the functioning of the system. To understand the functional aspects, a system can be thought of as (a) a set of elements (b) linked together in a purposeful way (c) to convert input into output. Inputs, mainly health resources, are processed through the system to create outputs, mainly health services. These services are an intermediate objective to the ultimate goal of improved health status for the population.[1] This notion is at the heart of the work on systems.

Starfield[12] has developed a model for understanding systems functions and for devising approaches to measuring the performance of the system. The definition of the health care system provided above leads to a focus on three components of the functioning of any health services system—structures, processes, and outcomes—and on two contextual areas, populations and the environment. These components and their interrelationships are displayed in the figure that follows.

Figure 1

The Health Services System



Source: Starfield, 1992

Structures

Measurement of the system's performance involves assessing its (1) structural elements such as facilities, staff, and financing (or inputs or health resources); (2) process, such as treatments or other health-promoting interventions (intermediate outputs or health services); (3) outcome (final outputs or health outcomes); and (4) their interrelationships. Historically, from a structural point of view, there has been very little oversight of health care systems in this country: they just develop. For example, financing and staffing issues related to primary care display little logic or purposefulness.

Populations

A system relates to a well-defined population that is being served. One critique of the current health care system is that it is not focused on populations but on individuals. In this case, the population is one of families with children who live in a geographic community. It is important to consider that the population consists of those who use health care as well as those who, for a variety of reasons, do not seek care.

Process

In contrast to the meaningful outcome measures available, process measures such as simple measures of utilization are not always meaningful and often do not indicate whether services meet needs. However, processes are very important to capture because they reflect the informational aspects of the system.

Outcomes

The objectives of the system are a logical place to begin. If one loses sight of the true objectives of the system, mistakes may be made in guiding the system into the proper channels for accomplishing its objectives.

Environment

At a minimum, environmental analysis should seek to explain the relationships between the system's environment and health status in a systematic way. This type of analysis should focus on an agreed-

upon set of explanatory factors. In this way, changes can be observed in these explanatory data over time and their impact on health status can be more readily assessed.[11]

A system operates within a larger environment. The environment of the system is what lies "outside" the system. However, defining the boundaries of the system can be a difficult task; this is especially true for child health. The environment of the health system, for example, includes the public education system, the public safety system, and the social welfare system, among others. These other sectors must be seen somehow as part of the system. Levey and Loomba[3] suggest that, instead of merely looking at traditional administrative and managerial boundaries, it may be better to examine how the system activities may influence processes in these external sectors. If, by some organizational change, the health care system can, for example, influence the educational system, then some of the educational process would belong inside the health system.

MEASURING THE PERFORMANCE OF SYSTEMS

Even the functional description of the system provided above still contains some ideas that are embedded and need to be made more explicit. These include, above all, an understanding of the nature of the communication and information processes that are at the core of the operation of a system. Without information, a system can't work toward its objective. The ability to measure the performance of a system depends on two major elements: information processes and standards.

Informational Aspects of Systems

As noted earlier, the central thread of any system is information that links the components of the system. A true "system" does not act in an uncontrolled way; rather, it gathers information about the resources used and how they were processed in order to adjust future actions so that they will be more likely to achieve the system's purpose.

The informational aspect of MCH systems has been a particularly weak aspect of Title V. Information functions were lost with the evolution of Title V. The turning point probably occurred with the advent

of the Block Grant, where the shift in authority to the states was accompanied by a reduction in reporting responsibilities. Until the reemphasis in 1989, Title V agencies at the state and federal levels gradually abandoned the important focus on continuously documenting the health and welfare status of mothers and children and studying resource and service issues. Systems for monitoring MCH health status have been inadequate; few systematic studies relating the structure of state MCH agencies to their performance have been conducted.[7] Further, public MCH agencies have been slow to extend documentation to include private as well as public sector structures or resources, so no complete pictures have emerged. However, the 1990s have seen a rebuilding of the informational components systems.

Standards for Performance

Any evaluation of a system's performance requires standards against which performance can be measured—either a preset goal (the normative approach) or a comparison of one system with another (the empirical approach).[12] These standards, values, and criteria must be applied to the system's attributes or operational characteristics. Thus the attributes of the primary care system—first contact, continuity, coordination, and comprehensiveness (see page 39)—provide a basis for evaluating primary care and a framework for assessing the level of attainment of primary care objectives.

CONCLUSION

Starfield[12] states that every health services system has two main goals: (1) Optimize the health of the population by employing the most advanced knowledge about health and disease; and, equally important, (2) minimize the disparities across population subgroups to ensure equal access to health services and the ability to achieve optimal health. In Starfield's view, "Primary care is the means by which the two goals of a health services system—optimization of health, and equity in distributing resources—are balanced."[12]

The focus on systems of care is likely to become more important with health care system reform. Government agencies with accountability functions, new organizations of providers and payors, and

other new structures will expect a higher level of performance from the health care system. New partnerships, infrastructure improvements, and mechanisms will be necessary to enable the health care system to operate with coherence, compatibility, and, ultimately, effectiveness. State MCH agencies will need to have a working definition of systems of care to guide their assessment and assurance functions.

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Delineating Public Roles in Planning, Providing, and Evaluating Primary Care Services for Children and Their Families

Les Nouveax Miserables—*Modern Victims of Social Asphyxia*

INTRODUCTION

Literature is replete with works depicting the plight of the disenfranchised who had to struggle over, around, and through societally imposed barriers. Health care has evolved into a complex maze of disjointed programs and conflicting eligibility standards. The current national struggle to define a responsive health care system has revealed a formidable array of barriers—structural, cultural, and financial—imposed on the health-seeking behaviors of individuals and communities. Society has elected to maintain certain tools of social and cultural isolation such as colonias, reservations, ghettos, barrios, slums, and housing projects. And if we believe we have progressed to an advanced societal plane, we need only gaze out onto the spinach fields of Colorado or look up into the

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orchards of the Pacific Northwest to witness child labor laws being violated. Collectively, these barriers and conditions impose a form of social asphyxia that creates victims who suffer from preventable and disproportionate morbidity and mortality.

This plight of individuals and a nation grappling with the consequences of a wholly inadequate health system is perhaps best illuminated by one literary masterpiece—*Les Miserables*. Victor Hugo's prose grasped the desperation of a population seeking reform. It reflects the same tensions and frustrations facing a growing percentage of this nation, business leaders, and the middle class who cannot access a system that was designed to improve quality of life and reduce suffering.

The preface to *Les Miserables* articulated a raison d'etre for that work which was appropriate for that time, and is a warning for our time as well as a justification for action:

> So long as there shall exist, by reason of law and custom, a social condemnation, which, in the face of civilization, artificially creates hells on earth, and complicates a destiny that is divine, with human fatality; so long as the three problems of the age—degradation of man by poverty, the ruin of woman by starvation, and the dwarfing of childhood by physical and spiritual night—are not solved; so long as, in certain regions, social asphyxia shall be possible; in other words, and from a yet more extended point of view, so long as ignorance and misery remain on earth, books like this cannot be useless.
>
> *Hauteville House, 1862*

Focus on Financing

The war on health care costs was unsuccessfully waged during the 1980s. The policy of deregulation created a postdated, large-for-gestational-age, fragmented $900 billion health care system. During the 10-year gestational period, the "fetus" experienced logarithmic growth as national expenditures more than doubled.[14] It had been anticipated that this period would usher in spending constraints to bring health care expenditures in line.

A large proportion of growth in health care expenditures was realized in the high-tech and tertiary care components of health care. Investment in preventive health services and primary care failed to keep pace. In many federally subsidized primary care programs (often a barometer of health priorities), appropriation levels actually declined or remained at base funding.[3] Less than 2.9 percent of all health expenditures were dedicated to support government public health and preventive activities in FY 1990.[4]

Per capita expenditures for health increased during this period; however, the nation experienced an erratic spending pattern which accentuated the difference in resources dedicated to the "haves" and the "have nots." Programmatic expansions for those at risk were accomplished primarily at the expense of other social programs or were so categorical as to be restrictive, confusing, competing, and of little utility.[5] Children with special needs, for example, often remained on the "disease-oriented express." In addition, when traditional curative medicine failed, opportunities to enhance functionality were not recognized or seized.

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Too much attention has been focused on a single issue of health care reform—financing. While one cannot downplay the significance of this issue as a motivator or incentive for change, reform will require a rethinking of our current medical delivery system to make it more patient-oriented and health-oriented. The present system has its roots in pathophysiology and has developed for the convenience of the provider of care.

Medical Involution

This same decade accelerated a process best described as medical involution—a process that coincided with an increasing focus on catastrophic care and resurrection medicine while simultaneously abandoning some effective community-based primary and preventive care strategies.[6,7] The

involution of medical care away from the community, away from populations at risk, and toward the tertiary care center began three decades ago and is now nearly complete. While the plight of rural Americans perhaps best illustrates this concept, the nation's inner cities have also suffered. Clinics, hospitals, and private practitioners have had to abandon high-risk populations in search of more profitable customers—those with third-party resources and access to these centralized delivery systems. Convenience for health professionals also played a role as they sought office space in proximity to the hospital and subspecialty groups.[2]

The process of medical involution created substantial nonfinancial barriers to care. As medicine left the community, transportation barriers evolved. Access to safe mass transit or barrier-free transportation often dictated who would receive care. The most vulnerable and frail were often excluded. It is clear that the process of medical involution was not for the convenience of the patient at risk.

A common theme defined those who were most adversely affected by medical involution. The impoverished and the socioeconomically deprived (often children) suffered disproportionately during this period, regardless of which portion of the life cycle they represented. Concomitantly, medical involution at the local level often coincided with the loss of other community infrastructural supports and resources such as social service agencies. The events compounded the adverse impact of medical involution on vulnerable populations.[3]

Medical involution accentuates the effects of cultural and ethnic isolation. As the nation ages, so do the minority populations of this country. While minority (particularly Hispanic) populations, on average, are younger, a growing percentage of minorities are reaching the geriatric age.

As medicine has clustered around central campuses, it has become increasingly difficult to provide care that is culturally and ethnically appropriate. The at-risk population often delayed timely care because of the culturally imposed barriers of centralized campuses. Efforts designed to deliver health care in the community by culturally appropriate health care professionals were to a great extent abandoned. Over the same period, small gains in the number of minority applicants entering medicine have been reversed.[4]

Compartmentalization

While medicine underwent a process of involution, we witnessed a parallel process within academia—compartmentalization. The pathophysiologic nature of medicine was adopted by payers of care and academic institutions. Interestingly, public health adopted a similar organizational schema often dictated by the need to respond to a specific disease or cluster of diseases. This disease-oriented trend was reinforced by patterns of reimbursement and priorities in medical research. These forces helped to sculpt a health care system based on a disease-oriented medical model. The system often is further subcompartmentalized by "organ system" into specific areas of subspecialization.

These factors—existing patterns of health care financing, priorities for research, medical involution, and compartmentalization—combine to deny this country a true health care system.

Medicine has failed (with the help of the payers of care) to effectively bring together these bundles or compartments of knowledge into a continuum of health care that can focus on the whole patient. The delivery system adopted this compartmentalized approach and fostered a categorical response to care. This created further barriers and confusion for patients or communities seeking help.

These factors—existing patterns of health care financing, priorities for research, medical involution, and compartmentalization—combine to deny this country a true health care system. To date, the country enjoys a superb medical system that is built on a foundation of pathophysiology. The trend in medicine has been to focus on diagnostic technologies and curative tactics. Preventive strategies and community and public health are largely neglected by medical education. The existing academic system often fails to create or cultivate role models that could reverse this trend.

The cumulative results of these events have contributed to the erosion of access to health care. In the United States, more than 39 million are uninsured; in the state of Texas, more than 3 million are uninsured, including 1.2 million children.[1,2,3]

An equal number are underinsured and lack adequate coverage for preventive services such as pap smears, mammography, immunizations, home care, or long-term care. Data indicate that, for certain segments of our population, we have actually lost ground nationally. African American males overall are dying earlier, and African American and Hispanic women suffer age-adjusted mortality for cervical cancer at rates more than twice those of Anglo women in Dallas County. Contrary to stereotypes, more than two-thirds of these persons work or live in the home of an employed individual.[2,3]

The emergence of a true health care system will require a more strategic focus that recognizes the rewards of preventive health services, understands the interplay of all "organ systems," and then recognizes the dynamics of a community that can affect the overall health status of a population. A health care system is able to aggregate and apply new knowledge to an identified at-risk population prior to their delayed visit to an emergency department. To be successful, this strategy of health must reverse some of the trends of the past three decades and provide care for the convenience of the seekers of care—not for the convenience of educators, students, researchers, and providers of care. The existing barriers must come down if there is to be a fundamental reform in health care delivery.

CHANGE AND INCENTIVES

Business and labor have become significant participants in the debate on health care financing and delivery. While labor disputes increasingly focus on health care issues, the business community is focusing more attention on preventive services.[3]

Proposed changes in health care financing also may be conducive to changing the current medical or curative system into a health system that "front loads" our investment with preventive services. For example, implementing relative value scales (designed to increase reimbursement for cognitive skills) could improve reimbursement and provide an impetus for preventive services. Similarly, reformulating methods to allocate Medicare dollars for undergraduate and graduate medical education

could encourage academia to promote primary care training and incorporate prevention within the medical school curriculum.[6,7]

Additionally, the increased sophistication of purchasers of care and the development of health promotion and disease prevention as product lines for many health care providers have many hospitals trying to position themselves for the anticipated change. The impact of these trends has begun to be appreciated by payors such as Blue Cross and Blue Shield, which recently released its list of reimbursable preventive services.

Innovative approaches designed to create incentives for both care providers and patients to practice preventive health are already in place in some systems.[7–9] Reductions of copayments and deductibles for patients who remain compliant with prescribed regimens are gaining favor. Increasingly, private practices, clinics, and health maintenance organizations are installing systems designed to "case manage" patients with the aid of reminder files, phone calls, and home visits.[8] Finally, some programs such as the Community Oriented Primary Care Program at Parkland Memorial Hospital (Dallas) encourage physicians to promote preventive care by linking incentives to the achievement of health outcomes, such as the reduction of breast cancer morbidity and mortality in a target community.

COMMUNITY-ORIENTED PRIMARY CARE AS A SYSTEM

The trend to shift patient care from the inpatient to the outpatient setting will continue, if for no other reason than the payors' desire to move care from a more expensive (better reimbursed) to a less expensive setting. This change in venue provides an opportunity for hospitals and their medical staffs to develop and implement new models of care that embrace preventive strategies and to position these systems to capitalize on changing incentives.

Significant steps have been taken in several communities to implement a community-based strategy, including the concept of community-oriented primary care (COPC). Developed by Dr. Sydney Kark and promoted through the World Health Organization and the Institute of Medicine of the National Academy of Sciences,[10] COPC is a way of practicing medicine that blends traditional primary care with public health services. It is designed to pinpoint at-risk populations in order to improve the health status of individual patients and the communities in which they reside. Whereas traditional medical practice or hospital-based care is oriented toward procedures, dollars, and the number of patients seen, Community-Oriented Primary Care is an outcome-oriented program that defines success in measurable epidemiologic results.[9,10]

Community-oriented primary care creates a framework for providing integrated care on a "one-stop shopping" basis, thus minimizing repetitive administrative costs and fragmentation of care. The "one-stop" concept also reduces barriers to care (such as transportation) by co-locating such related services as well-child, sick-child, immunization, health screening, and education services.

The concept is predicated on the ability of a health care entity to understand and take responsibility for the health care needs of a population or defined community. Epidemiologic principles are applied to identify areas of need and populations at risk. The community participates actively in identifying and prioritizing its own health needs. Resources are focused on health problems that are prevalent, preventable, and have the most adverse effect on the target population. The system is structured to deliver a comprehensive array of health services within a preventive framework.

Consistent with the COPC program philosophy of delivering nontraditional care in nontraditional settings, outreach teams provide primary health care, prevention, nutritional assessments, and social services in schools, churches, centers for the elderly, and homeless shelters. While this type of care is often nonreimbursable, it is clear that these services reinforce health-seeking behaviors and identify individual health problems and potential public health issues.

THE DALLAS MODEL

In Dallas, Parkland Memorial Hospital has implemented a large Community Oriented Primary Care Program supported in part by county taxes. The program currently focuses on health services in six at-risk communities in Dallas County that were identified in a countywide needs assessment conducted by Parkland. The program is affiliated with The University of Texas Southwestern Medical Center at Dallas and the Geriatric Assessment Team at Parkland. Physicians working in these centers are granted faculty status by the university and provide attending coverage for the inpatient units of Parkland. This arrangement enables the Community Oriented Primary Care Program to provide continuity of care between the community practice and inpatient settings. The program operates six health centers handling more than 100,000 patient visits annually. A seventh center opened in southern Dallas in spring 1991. A total of more than 200,000 patient visits are projected to occur annually.

Minority health professionals such as physicians and social workers, many of whom live in the communities they serve, provide culturally appropriate role models. Bilingual staff minimize barriers to care. The COPC program has the staff expertise to provide translations in Spanish and five other languages.

Dallas County Health District's two years of experience in implementing the community-oriented primary care concept has generated some significant results in the areas of health policy, financing, organizational structure, community assessment, and health services utilization. Although the program has been in operation for less than three years, it has increased health services capacity in several at-risk communities defined by the original needs assessment, and has maintained existing services in several communities that were in danger of losing their service providers.

Due to the initial success of the program and its focus on program accountability through assessment of health outcomes, both the County of Dallas, which provided the initial vehicle to fund the COPC program, and the City of Dallas Health Department formally adopted the concept of

community-oriented primary care. In 1991, the Dallas City Council approved the strategic agenda whereby the city's Department of Health and Human Services would make the transition toward a model of health service delivery that embraced the concepts of community-oriented primary care. This commitment was formalized through a memorandum of understanding with the Dallas County Hospital District. The memorandum called for implementation of joint planning and programming for community-based health services; more than $750,000 was programmed into the defined communities collaboratively, enabling previously fragmented delivery systems to be combined in several locations throughout the city.

Financing the Community Oriented Primary Care Program has remained a priority for the Dallas County Hospital District through a separate component of the county's *ad valorem* tax system. This rate is established annually by the Dallas County Commissioners Court and was increased for FY 1992 to meet anticipated increases in service demands and to expand the scope of services such as health education, outreach, and nutrition. The program receives approximately 56 percent of its funding through the *ad valorem* tax base while the remainder is derived from patient collections and through funding from 16 grants.

The program's organizational accomplishments have facilitated the growth of the program budget from $250,000 in FY 1989 to more than $12 million in FY 1993. The COPC program has provided a conceptual framework and platform to consolidate a fragmented array of existing health services.

Four distinct community-based health centers were merged under the COPC umbrella during 1990 and 1991. These mergers reduced duplication of services and administrative costs by $300,000 and maintained more than $3.5 million in state, federal, and private resources already targeted to support these separate community-based health care entities. More significant, the consolidation of these preexisting centers under one umbrella agency enabled the COPC program to use the savings from reduced administrative overhead costs to augment services at existing health centers. These enhanced services typically included nonreimbursable services such as outreach, health education, social services, and nutrition.

The initial needs assessment, conducted by the Dallas County Hospital District, provided critical data relevant to the health needs of the entire county. The methodology expanded the traditional indicators of underservice, including criteria for federal designation as a Medically Underserved Area or Health Professional Shortage Area. The methodology used by the Dallas County Hospital District reviewed relevant mortality and coronary artery disease. The data were enhanced through an analysis of diagnostic data and utilization patterns of patients presenting to Parkland Memorial Hospital. The data derived from Parkland were geocoded to determine patient origin information and to target communities that rely disproportionately on Parkland for episodic and hospital care.

Although this initial effort identified eight distinct communities with critical health needs, a formal effort to reevaluate the county was not instituted initially. In 1990, the COPC program began to develop a methodology to obtain denominator data from the community. The goal was to use an instrument that was reliable and valid, and that could be aggregated and then compared to a larger standard data set at county, state, or national levels.

To meet these requirements, the program initiated an effort to further delineate community health needs within Dallas County. The method oversamples defined communities (Standard Statistical Communities) using the National Health Interview Survey (NHIS). This methodology has targeted southern Dallas and is a collaborative effort of the Census Bureau and a VISTA volunteer program. This initial assessment was completed in late 1991, after 1,500 households had been surveyed in the southern Dallas area. The data will enable the program to assess needs and consider revisions in the current programmatic strategy and budget. Findings will be validated using focus groups from the surveyed community.

The goal of this effort is to establish an implementation schedule for the National Health Interview Survey to be applied throughout the county. This strategy will target all areas of the county and will reevaluate defined communities every five years. The plan may be modified based on data obtained through focus groups or from other sources such as vital records or census data.

The program has recently completed a hospital utilization study comparing pediatric admission rates and charges in four areas of the county. This analysis sought to determine whether there were differ-

ences in utilization and gross hospital charges between communities served by a COPC program and those not currently served by a community-based center.

The four communities were stratified by socioeconomic status and demographic data. The west Dallas community, which had a long-standing COPC pediatric program, was found to have lower hospital utilization compared to the other three communities. West Dallas had the lowest per capita income and one of the highest percentages of minority populations. Significantly, west Dallas had a lower admission rate, one of the lowest gross charges per admission rate, and one of the best collection/charge ratios, indicating that patients were becoming certified for Medicaid through the COPC program.

Trend analysis, conducted in the 1980s, indicates that, with implementation of the community-based program, there has been a decrease in the admission rate and emergency room utilization in both Parkland Hospital and Children's Medical Center for children under 17 living in west Dallas. This trend has not been found in the other parts of the community using these two centers for hospital care.

FROM HERE TO THERE

In 1992, the Texas Legislature passed House Bill 7 which reconfigured the state's 11 health and human services agencies. Among the changes included in the bill was the transfer of the acute care portion of Medicaid to the Department of Health. This legislation provided the opportunity for the department to integrate this large program with an array of smaller, categorical health care programs.

Given the success of comprehensive community-based systems of care for the delivery of family health services, the Texas Department of Health established a new programmatic effort that will better meet the needs of children and families. The department developed a new Bureau of Community Oriented Primary Care to bring together many of the public health programs established by the Indigent Health Care Act of Texas (1985), Title V, primary care programs, the Special Supplemental Nutrition Program for Women, Infants and Children (WIC), and Medicaid/Early and Periodic

Screening, Diagnostic and Treatment (EPSDT), and to link these programs into strong community-based, family-centered health systems meeting both the acute and preventive health service needs of the local population.

The purpose of this new bureau will be to provide support for the development of community-based primary care health centers to assist communities in identifying and prioritizing their own health needs and to provide a feedback loop to strengthen the comprehensive health services offered. Programs established through this initiative will reduce the current fragmentation of services. Prevention will be a major focus, and the centers are expected to track health outcomes and measure the effectiveness of the services provided.

Finance reform will drive change but will not be sufficient to identify and respond to prevalent health problems facing our urban and rural communities, including the need for professionals trained to deliver comprehensive preventive care.

This refocusing of services to the community level through the mixing and matching of funding services includes a strategy to promote COPC within newly established Medicaid managed care contracts. The Bureau of Community Oriented Primary Care will have the added responsibility to position communities for reform by developing new or expanded primary care capacities. This is particularly critical in Texas, where more than 170 of the state's 254 counties are now designated as Medically Underserved Areas and parts of 52 additional counties are so designated. Without a focus on infrastructure, the state will not be positioned to provide access to the estimated 3.5 million Texans who are uninsured for health care.

As part of this effort, the Bureau of Community Oriented Primary Care will focus resources on expansion of school-based services that can target the needs of school-age children and the surrounding community population. The state already has several such models that have demonstrated their effectiveness at reducing vaccine-preventable disease, emergency room use, and hospital

admissions.[11] Rural and urban centers will be funded and designed to encourage public, private, and academic physicians to participate in delivery of comprehensive primary care. Many communities are hopeful that such grants will assist them in recruiting physicians or midlevel providers (through the opportunity to have an expanded practice focus) and in hiring nontraditional staff such as health educators, nutritionists, social workers, and school counselors. The school-based initiative will be incorporated into the Medicaid managed care effort.

CONCLUSION

The health care landscape is changing, and further change can be expected. Health strategies that anticipate these changes will benefit the communities they serve. Innovative models of care that incorporate preventive health services will benefit the health of our citizens and produce incentives to become healthier communities.

Patient-centered therapeutic partnerships can best be established in community settings (as opposed to acute care environments). Models such as community-oriented primary care, which integrate prevention into their acute care delivery systems, are better positioned to respond to prevalent health problems and reduce preventable morbidity and mortality.

While the current health reform debate has focused predominantly on financing strategies that address cost containment, it is imperative that reform efforts focus on accessibility and quality of care benefits for all Texans in need, including those at greatest health risk. Finance reform will drive change but will not be sufficient to identity and respond to prevalent health problems facing our urban and rural communities, including the need for professionals trained to deliver comprehensive preventive care.

Finally, a preventive health strategy provides a conceptual framework that is logical and that challenges our present preoccupation with crisis medicine, including resurrection and curative tactics. A trend that embraces health through provision of preventive services would refute the title of a "pay later" society and position this country to avoid needless human suffering and medical costs.

REFERENCES

Assessing the Status of Primary Care Services

A Working Approach

In most of the Western industrialized world, primary care is the cornerstone of the health system. Easily delineated from consultative and referral care, it is clearly identifiable. In contrast, primary care in the United States is poorly understood and primitive in its development. Family practitioners, who comprise approximately 10 percent of physicians in the country, are the counterparts of the general practitioners in other comparable countries. General internists and pediatricians, however, are more of a hybrid, with a substantial proportion devoting at least part of their professional time to subspecialty practice.

by
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THE BENEFITS—AND CHALLENGES—OF PRIMARY CARE

Evidence of the benefits of primary care, as assessed through various measures of the process and outcomes of health services, is beginning to reach the scientific literature.[1] Geographic areas with higher proportions of primary care physicians relative to specialists have lower mortality rates from most types of conditions[2] and from undiagnosed conditions.[3] Individuals with an identifiable source of primary care are more likely to have their chronic conditions well controlled than individuals without such a source.[4] Satisfaction with health services and indicators of health are generally higher in countries with more developed primary care systems.[5]

Rapidly escalating costs of care have led to emerging interest in primary care within the United States. The imbalance in the numbers of primary care and specialty physicians is widely recognized as being at least partly responsible for excessive costs. Some health care reform proposals address this issue directly by providing incentives to produce increased numbers of primary care physicians relative to specialists. In a landmark action, the American Board of Family Medicine and the American Board of Internal Medicine joined forces to promulgate a definition of primary care that fits the concept of primary care in other countries. Primary care can be defined as *continuous, comprehensive, and coordinated care provided to populations undifferentiated by gender, disease, or organ system.*[6] Acceptance of this definition will provide the country with a good basis for planning and evaluation of primary care.

Decades of inattention to the deterioration of the primary care structure of the U.S. health system have left the system of medical education unprepared to deal with the new challenge to reorient medical practice. The tradition of hospital-oriented training is unsuited to training for practice in the community. Most faculty in medical schools are specialists who have little knowledge of the way in which problems present to physicians in the community, and the preponderance of focus on patients with more unusual diseases produces physicians who overestimate the likelihood that the patients

they see will have such problems rather than the more common ailments (many of them undiagnosable) encountered in primary care. As a result, they carry out more diagnostic tests and generate higher costs than are warranted.

Poor training for primary care also results in a lack of attention to the important and unique correlates of primary care practice: long-term relationships with individuals as persons (distinct from individuals characterized by the presence of a particular disease); comprehensiveness of care that includes attention to prevention, mental health, and the impact of social conditions in compromising health; coordination of services with a responsibility to integrate all aspects of care received by individuals in the course of their illnesses; and achievement of first-contact care, which implies an accessibility and availability to meet health care needs at the time they occur rather than at the physician's convenience.

Decades of inattention to the deterioration of the primary care structure of the U.S. health system have left the system of medical education unprepared to deal with the new challenge to reorient medical practice.

Apart from these four features that are unique to primary care, several other aspects of primary care need to be incorporated into training. Two of these—community orientation and family centeredness—may be considered derivative features since they are actually an extension of comprehensiveness. In other words, for health service providers to be highly effective in recognizing the health needs of their populations and providing the full range of services needed to deal with them, these providers will have to be community oriented and family centered. One other feature—cultural competence—is often included in the requirements for primary care. Since all levels of health care (including consultative and referral care) should be provided with attention to different cultural needs, cultural competence is essential but is not unique to primary care.

MEASUREMENT OF THE ESSENTIAL ELEMENTS OF PRIMARY CARE

Fortunately, it is now possible to define and measure both the unique aspects of primary care and its derivative and essential features. Drawing from the definition stated above, primary care is continuous over time (or longitudinal), focused on the patient as a person (regardless of the diagnosis or organ system involved), comprehensive, and coordinated. Primary care also is first-contact or the first point of entry into the health care system for new problems. These are the unique features of primary care.

The important and unique correlates of primary care practice are long-term relationships with individuals as persons, comprehensiveness of care, coordination of services, and achievement of first-contact care.

Other levels of care may aspire to one or more of these features (for example, emergency services may be first-contact). But only primary care assumes responsibility for all four. In addition, primary care includes derivative features: family centeredness and community orientation. They are derivative because they are achieved by high levels of performance on the unique features of primary care. Other features are essential but not unique, because they are shared with other levels of care. They entail such features as cultural competence.

Each of the features of primary care can be represented by some structural feature of the health care system and by another feature that reflects the desired behavior. The structural feature makes it possible for the practitioner to provide services in certain ways, and the process feature is the desired behavior itself. Measurement of both makes it possible to determine whether the health services are designed to deliver primary care services and whether the services actually are delivered in the appropriate way.

Structural Features of Primary Care

The structural features to be considered in an evaluation of the potential for delivering primary care are (1) arrangements for accessibility to services, (2) the extent to which a formal relationship exists between a provider or team of providers and the specific individuals, (3) the range of services offered by the provider(s), and (4) the existing arrangements for continuity (in both personnel and records).

Arrangements for accessibility are necessary if the facility is to be used as the point of first contact. If the facility does not arrange to provide services that are congenial in time, place, and accommodations, people either will not seek care or will seek care where it is more accessible and available.

A formal relationship between practitioners and patients is important for longitudinality. This type of relationship can be symbolized by the presence of a roster of patients for whom the practitioner is responsible, and by a formal or informal contract that recognizes this relationship at least for a given period of time.

Achievement of comprehensiveness requires that the facility have available a range of services needed to deal with common problems in the population. Many of these common services are the same, regardless of the population served. Some, however, may be unique in certain populations. For example, in areas where substance abuse is high, its management should be part of primary care rather than referral services. The key consideration is deciding between those services to be required in primary care and those services that can be arranged for by referral, based on the frequency of the problem in the population served.

The structural requirement for achieving coordination is a mechanism to ensure communication of information. Conventionally, this repository of information consists of the practitioners themselves, aided by medical records and other information systems. Studies have shown, however, that information transfer can be enhanced by improvements in medical records and by more effective team work in health care facilities. Some innovative practices are exploring the benefits of having patients review or even keep their own medical records—this information can be very useful in helping prac-

titioners coordinate care and avoid unnecessary and perhaps inappropriate interventions. Each of these four structural features is necessary in the evaluation of the potential for first-contact, for longitudinality, for comprehensiveness, and for coordination of services.

Process Features of Primary Care

The achievement of high performance levels of primary care can be assessed at two levels—the level at which use occurs (i.e., the facility) and the level of the population. To assess the level of the facility or provider, the experiences of those using the facility are determined. The perspective of users of facilities are likely to be very different from those of non-users, and it is important to recognize that information obtained from users may give an entirely different cast to the evaluation of care than that obtained from individuals in the community. Non-users, even if they are enrolled in a facility and report it as their "regular source of care," are more likely to have experienced barriers to seeking care, and may be more ill and therefore less able to use services when effort is required to reach them.

Thus, great care must be taken when interpreting the results of surveys of users of facilities, especially if the sample of individuals surveyed is chosen from daily lists of visitors. These lists will overrepresent more frequent users, who are more likely to be those who find it easiest to get to the facility. A better sampling frame is a list of those who made any visit to the facility in a period of time (such as one year or two years), since it is much less likely to overrepresent frequent users. The best way to assess a population's experiences with primary care services is to take the sample from a list of enrollees (those who are eligible to receive care from the facility). This sample will include users as well as non-users and will provide a more accurate view of access and satisfaction with services than will a user-oriented approach.

The behavioral (or process) features that are responsible for translating the potential into a reality have to do with patterns of utilization and the extent to which practitioners in the facility recognize the problems experienced by patients and existing in the community at large.

First-contact care is achieved when people seek their care first from the provider or facility, rather than going elsewhere (to a specialist or emergency service, for example).

Longitudinality is achieved when both the provider and patient recognize that they know each other and have a mutual relationship that is manifested when that practitioner is involved in all aspects of the patient's care, not just the patient's specific problem.

Comprehensiveness is achieved when it can be demonstrated that all common problems in the enrolled community or patient population are being handled in primary care rather than by referral, and when all problems or health concerns experienced by patients are recognized by the provider. It is in the area of comprehensiveness that issues related to the provision of all types of services are of concern, for both mental and physical health problems, and with regard to care of acute conditions, ongoing care for people with special health needs, and preventive care.

Coordination is achieved when information about people that derives from visits elsewhere or to other health related services is transmitted to and recognized by the primary care provider.

MEASUREMENT OF THE OTHER FEATURES OF PRIMARY CARE

Like the unique features of primary care, the derivative and essential features can be measured using the same framework.

Community Orientation

Community orientation involves consideration of several structural characteristics: (1) Definition of an eligible population, (2) information systems, and (3) governance mechanisms.

First, in order to focus on the community, the population must be defined in such a way as to characterize it.

Second, information systems that reflect existing health problems must be in place. One of the important roles of the public health sector has been to develop information on community health needs, by means of vital statistics systems, surveillance mechanisms (such as reporting systems and case registers), and special surveys (such as the National Health Interview Survey). The challenge posed by health care reform is to integrate these traditional public health data systems with clinical data systems; the combination of the two will enable responsible agencies and health systems to gain a full picture of health needs of their communities.

Third, governance mechanisms are also important in achieving community orientation, since the community itself should be involved in setting priorities for its health care, given information obtained from data systems concerning existing health needs.

Family Orientation

Family orientation has at least two components. The first involves the recognition of clusters of illness or predisposition to illness as a result of either genetic or shared socioenvironmental exposures. The second involves consideration of family dynamics that influence the family's recognition of existing health needs and also influence an individual's ability to use health services and to benefit from them. Thus, family orientation requires data systems that prompt inquiry into family dynamics and interrelationships and also requires the provision of a range of services that address these family characteristics.

Cultural Competence

The final characteristic of primary care—an essential but not unique aspect—is cultural competence. Cultural competence is facilitated by addressing the personnel component of the structure of services. Employing staff with cultural characteristics similar to those of the population served is one mechanism for incorporating cultural sensitivity into service provision. The structural feature of governance is also pursuant to cultural competence, since representation of community members will provide a perspective that otherwise would be lacking.

EVALUATIONS OF PRIMARY CARE SYSTEMS

This framework has led to several evaluations of primary care. The first evaluation came at the request of the local medical society. In response, Weiner et al.[7] evaluated the extent and distribution of primary care services available to the population of an entire metropolitan area. The assessment relied upon information obtained in a sample of office practices of different types of specialists. Both patients and office staff were queried to obtain information on both structural and behavioral features of primary care.

Wilson et al.[8] assessed the extent to which their pediatric primary care teaching practice attained levels of primary care equivalent to those in the community at large, and Barker et al.[9] determined whether their internal medicine training program attained a pre-set level of performance on the features of primary care. Both of these studies relied on information from medical records rather than practitioners or patients.

Black[10] used both claims and survey data to determine the extent to which certain aspects of primary care were achieved by a sample of elderly residents of an entire Canadian province. Noble et al.[11] applied the same framework to a comparison of residencies in both internal medicine and pediatrics, using information obtained from queries of directors of clinical facilities. They found that training programs designed to be primary care oriented were, in fact, attaining higher levels of performance on the structural features of primary care than were conventional training programs.

The staff of the Child and Adolescent Health Policy Center at The Johns Hopkins University have been exploring the possibility of applying the method to assessing primary care provided to children in several entire states. The specific experiences of the Child and Adolescent Health Policy Center in developing assessment instruments for such use are described in "Assessing the Status of Primary Care Services: Early Experiences of the Child and Adolescent Health Policy Center in Evaluating Primary Care" in this volume (page 63).

REFERENCES

Developing Population-Based Data Sets at National, State, and Local Levels

Potential and Promise

NEED FOR POPULATION-BASED DATA

To design, implement, and monitor a community-based, consumer-oriented, culturally competent primary care system for children, adolescents, and their families, a population-based data information system must be available. Without the development of such a data system, public health entities in the future will not be able to carry out the core public health functions of assessment, policy development, and quality assurance[1] at local, state, and federal levels.

Today, public health agencies do not perform all three of these core functions across the health care system. We must advocate for a future of public health in which all of these roles or functions throughout the entire health care system (whether financed with public or private dollars) are inte-

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grated at state and local levels. To accomplish this goal, traditional surveillance and vital statistics databases in public health departments will need to be managed and analyzed, along with health status outcomes from a variety of primary care and other clinical settings. The consumer health "report card" of the future should include information on patient outcomes in various ambulatory and inpatient settings as well as the health status of the entire community. All data in these community and facility report cards should be available by key indicators (such as race/ethnicity, health care payor, and others).

Consistent, effective, ongoing policy development and program evaluation can be achieved only when a population-based responsive data system is available. Information from an integrated population-based data system potentially can be used to:

1. Conduct local and state needs assessments;
2. Monitor state-mandated programs/screenings;
3. Comply with federal data reporting requirements (Title V, Medicaid, *Healthy People 2000* objectives);
4. Direct program planning and management;
5. Conduct program and service evaluations; and
6. Assure follow-up services after identification.

To meet these objectives, the data system must use standard definitions, and must be comprehensive in scope, accessible via computer technology and information highways of the future, updated regularly with the most current year's data, and available for a range of geopolitical entities (census track, zip codes, town, county, city, region). Given today's technology, a system can be designed and connected at many levels so that billing, patient monitoring, and quality assurance can take place at local provider levels. Selected subsets of aggregate or individually identifiable data can be shared at larger geographic levels (city, county, state) for health planning, monitoring of health status, and quality assurance.

Many current data initiatives exist at all levels of government and in the private health care industry; however, there has been little planning or discussion of how these initiatives fit together to form a

population-based data system that can be used by a variety of stakeholders in planning and monitoring a primary care system for children and youth. Most of today's data initiatives have been developed to meet the needs of (1) a specific health content issue (such as immunization rates, HIV reports, adolescent pregnancy rates), or (2) a specific management information system (such as measuring distribution of food vouchers to women and children eligible for Special Supplemental Nutrition Program for Women, Infants and Children [WIC] services, or tracking entry into prenatal care or early intervention programs). Most maternal and child health (MCH) data sources have evolved only because of available funding to meet a particular requirement at the state or federal level.

State and national health care reform debates offer many opportunities to discuss the need for a population-based data system to track the health status of the population by various provider arrangements and to monitor the impact of changes in access to health care over time. Current state reform initiatives in managed care, adolescent health, school health, and children with special health needs should be used as mechanisms for developing a population-based data infrastructure.

A population-based data system with quantitative information on health status and health service utilization patterns will always be a starting point for local needs assessments and evaluations. Since no data system will be expansive enough to answer all questions related to health status and health planning at the local level, qualitative information and local data will most likely need to be collected from focus groups, individual interviews, and local data sources to enhance the meaning of the health indicators generated in a population-based child health data system.

Finally, a community-level population-based data system potentially can help document the cost savings of community prevention and health promotion activities as well as the functioning of various primary care practice arrangements within a community. The data generated will not only assist parents in choosing primary care providers for their children, but will also assist parents and others to advocate for and participate in community system changes needed to enhance the health status of children and youth in their locality. Since none of these activities can happen effectively without having population-based data available to all, we should begin to build these maternal and child health data systems.

CATEGORIES OF INFORMATION

A population-based data system at any level of accountability should include data in four major categories: health status measures, service utilization indicators or process measures, sociodemographic and environmental measures, and behavioral risk indicators. Indicators in any of these four categorical areas can range from a minimal set of core items to an expansive list of items offering rich detail and elaboration in a particular health area.

Both in the literature and in practice, the debate continues about which items should be included in a population-based data system spanning the age range from birth through adolescence.[7] Special concerns involve adequately addressing race and ethnicity so that planning and health status monitoring can be conducted effectively for these subgroups, and can include data on the health outcomes of subgroups such as children with special health needs (rather than eliminating health outcomes data because of lack of agreement about how to assess health functioning).

Examples of items in the four categories comprising population-based data systems are presented in tables 1 to 3. Table 1 lists the items used in the Harvard Community Child Health Studies to assess health status and evaluate maternal and child health services in counties in Michigan and Massachusetts.[7] This example illustrates the breadth and depth of information that can be collected in all domains using a variety of data sources. Tables 2 and 3 provide examples to illustrate minimal data components (see pages 55 and 57).

Under the State Systems Development Initiative, all state Title V MCH agencies have been awarded enhanced grants to assist state efforts to build community-based, family-centered systems of primary care for children and youth. One goal of the Massachusetts Child Health 2000 Systems Development Initiative is to develop and implement a core minimal data set for primary care providers in the state. Draft recommendations for this data set are listed in table 2.

Massachusetts and the five other New England states are also participating in the development of a model school health information system. This MCH data enhancement project presents a unique

Table 1

Harvard Community Child Health Studies Measure

Child Health Status Measure

Mortality
- Infant (Perinatal/Neonatal/Postnatal by cause)
- Childhood (by cause)

Morbidity
- Birth Outcomes
  - Low Birthweight
  - Prematurity
- Acute Illness (past two weeks)
- Chronic Illness or Conditions
  - Asthma
  - Hay Fever
  - Other Allergies
  - Kidney Problems
  - Heart Problems
  - Hearing Difficulties
  - Vision Problems
  - Speaking Difficulty
  - Missing Extremities
  - Permanent Stiffness/Deformities
  - Birth Defects
  - Paralysis
  - Mental Retardation
  - Arthritis
  - Epilepsy or Convulsions
  - Other Seizures, Fits
  - Cerebral Palsy
  - Diabetes
  - Obesity

Functioning
- Physical
  - Limitations due to Chronic Condition
  - Self-Help Skills/Independence
  - Activities of Daily Living
- Psychosocial/Behavior
  - Behavior Problem
  - Social Problem with Peers/Adults
  - Runaway from Home
  - Diagnostic Screening Inventory for Psychiatric Impairment* (16–17 only)
  - Self-Destructive Tendencies
  - Mentation Problems
  - Conflict with Parents
  - Aggressive Anxiety
  - Fighting
  - Delinquency
  - Isolation
  - PARS II Adjustment Scale* (16–17 only)
  - Peer Relations
  - Dependency
  - Hostility
  - Productivity
  - Anxiety/Depression
  - Withdrawn
  - Preschool Behavior Scale* (3–5 only)
  - Cognitive/Academic
  - School Status (Grade Level, Grades)
  - Special Placement
  - Learning Problem
  - School Problem
  - General Functioning
  - Bed Disability Days
  - Absences from School
  - General Health Status Rating
  - Health Habits
  - Drug Use**
  - Alcohol Use**
  - Cigarette Use

Process Measures/Service Utilization Indicators

Access Measures
- Insurance Private/Medicaid/etc) Coverage
- Supply of Health Professionals in the Community
- Regular Source of Medical Care
- Knowledge and Awareness of Services
  - Early Intervention Programs
  - Well-Baby/Immunizations Clinics
  - WIC
  - Mental Health Counseling Programs
  - Department of Social Services
  - Department of Public Health
  - Head Start/Child Development
  - Crippled Children Services
  - Poison Control Center Phone Line
  - EPSDT
  - AFDC
- Knowledge and Application of Law PL 94-142

Early Childhood Specialist

Utilization of Health and Health Related Services in the Community
- Professional care during the past year
- Pediatrician (primary care specialist)
- Dentists
- Ophthalmologist/Optometrist
- Nurse or Nurse Practitioner (office)
- Public Health (counseling, school)
- Social Worker
- Psychiatrist/Psychologist
- School Guidance Adjustment Counselor
- Child Psychologist/Psychiatrist/Therapist
- Family Therapist
- Speech Therapist
- Physical Therapist
- Occupational Therapist
- Chiropractor
- Genetic Counselor
- Services used during the past year
- Early Intervention Programs
- Well-Baby/Immunizations Clinics
- WIC
- Mental Health Counseling Programs
- Department of Social Services
- Department of Public Health
- Head Start/Child Development
- Poison Control Center Phone Line
- EPSDT
- AFDC
- Legal Services
- Educational Services Placement
- Hospitalizations (past year)
- Immunization Rates (school entry)
- Medication Use

Table 1 (continued)

Harvard Community Child Health Studies Measure (continued)

Social, Family and Other Environmental Measures		
Parental Characteristics •Education •Employment/Occupation •Health Status •Health Habits Cigarette Use Obesity	Family Characteristics •Family Structure and Composition* •Family Functioning* •Poverty Income Status •Parents Martial Status •Sibling's Psychological Status* Social Supports in Community	•Group Memberships* •Help with Child Care Tasks Environmental Measures •Neighborhood Environment •Air Pollution •Crowding •Fluoridation

* Chronically ill sample only
** Youth sample only

Source: SL Gortmaker and DK Walker (1984).

opportunity to standardize data collection on student health status indicators in order to permit data analysis for needs assessment, planning, program monitoring, and evaluation at local and state levels. As part of this system, Massachusetts will pilot an entry-into-kindergarten data set, with a future goal of permanently establishing a second population-based data collection point in childhood. Recommendations for minimal entry-into-kindergarten data are listed in table 3 (see page 57).

POTENTIAL POPULATION-BASED DATA SOURCES

Table 4 lists potential population-based data sources available at federal, state, and local levels in four major categories: surveys, vital statistics, surveillance systems/disease registries, and program/service management information systems. Although many data sources are currently available, significant issues concerning content and use of these sources have resulted in a dearth of information available for local and state planners and evaluators of child health primary care systems.

Most surveys available today provide data at the national level; however, the need for population-based data for planning and monitoring is acute at the state and local levels. All of the national surveys (see table 4, page 58) would provide valuable information for state and local levels if the samples

Table 2

Recommendations for Pediatric Primary Care Minimum Data Set

Item	*Indicator*
1.	Personal identifier: name, number, or both
2.	Mother's identifier: name, number, or both
3.	Residence code or zip code or address
4.	Date of birth of child
5.	Sex
6.	Race of child or of mother and father
7.	Ethnicity/ancestry of child or of mother and father
8.	Language most often spoken in the child's home
9.	Type of insurance coverage...public, private, none
10.	Evidence of developmental delay (Yes/no)
11.	Chronic, disabling condition or disability (Yes/no)
12.	Limited parenting, inadequate shelter, open or confirmed protective service investigation, substance abuse in the home, family conditions (Yes/no)
13.	Environmental hazards, use of tobacco in home (Yes/no)
14.	Evidence of problematic source of primary care (past problem or present access problem) (Yes/no)
15.	Date of visit
16.	Type of visit (emergency, sick visit, follow-up, well visit)
17.	Provider code
18.	Problem or diagnosis
19.	Disposition (death, referral, follow-up, concluded episode)
20.	Adequate immunization status at encounter (Yes/no)
21.	Height
22.	Weight
23.	Hematocrit

Source: Child Health 2000 Systems Development Initiative, Bureau of Family and Community Health, Massachusetts Department of Public Health (1994).

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Table 2 (continued)

Recommendations for Pediatric Primary Care Minimum Data Set (continued)

Item	*Indicator*
24.	Emergency department use > use *x* times in the past year (Yes/no)
25.	Hospitalization use > use *x* times in the past year (Yes/no)
26.	Asthma (Yes/no)
	For children under 2
27.	Breastfeeding 4 months postpartum (Yes/no)
	For children under 6
28.	Blood lead level or EP level
29.	WIC status (Not eligible, Enrolled, Referred and pending)
30.	Early intervention status (Not eligible, Enrolled, Referred and pending)
	For children 6–11
31.	School progress (grade level for age): Average/Below
32.	Vision screening: normal/abnormal
33.	Hearing screening: normal/abnormal
34.	Scoliosis screening: normal/abnormal
	For adolescents 12–18
35.	School progress, grade level for age (Average/Below/Drop Out)
36.	Substance abuse issues (Yes/no)
37.	Sexually active (Yes/no); Using birth control (Yes/no)
38.	Mental health concerns (Yes/no)

Source: Child Health 2000 Systems Development Initiative, Bureau of Family and Community Health, Massachusetts Department of Public Health (1994).

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Table 3

Recommendations for Entry-Into-Kindergarten Data Set

Item*	Indicator
	HEALTH STATUS MEASURES
1.	Immunization data
2.	Heights and weights
3.	Chronic illnesses/conditions/disabilities
4.	Blood/lead and hematocrit levels
5.	Vision and hearing
8.	Physical examination
11.	IQ test/school readiness
13.	Psychological factors: affect of the child, ability to relate to others, etc.
14.	TB screening
15.	Dental screening
16.	Medication
	SERVICE UTILIZATION INDICATORS
6.	Insurance coverage
7.	Regular source of medical care
10.	Emergency department use/Hospital days
17.	School lunch program participation
	SOCIODEMOGRAPHIC/ENVIRONMENTAL MEASURES
12.	Home environment (homelessness, protective custody, etc.)
19.	Fluoridation (through public system and /or participation in school program)
20.	Family structure and composition
	BEHAVIORAL RISK INDICATORS
18.	Use of tobacco in the home

*Items are listed in priority order (1 = highest priority)

Source: Model School Health Information System, Bureau of Family and Community Health, Massachusetts Department of Public Health (1994)

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Table 4

Potential Population-Based Data Sources

SURVEYS
National Health Interview Survey
1981 and 1988 Child Health Supplements
1992 Youth Risk Behavior Survey
National Hospital Discharge Survey
National Health and Nutrition Examination Survey
National Survey of Family Growth
National Medical Care Utilization and Expenditure Survey
Vital Statistics Follow-back Surveys
Census and Current Population Survey
National Longitudinal Survey of Youth (including child supplements)
Other National, State, or Local Surveys (e.g., State Household Surveys, School Adolescent Surveys, Special Focus Surveys, Provider Surveys, etc.)
VITAL STATISTICS
Birth Registration System
Death Registration System
SURVEILLANCE SYSTEMS/DISEASE REGISTRIES
Pediatric Nutrition Surveillance System
Communicable Disease Reporting Systems (e.g., SIDS, HIV, etc.)
Cancer, Birth Defect and Other Disease Registries
PROGRAM/SERVICE MANAGEMENT INFORMATION SYSTEMS
Hospital Discharge Data
Insurance/Billing Data
MCH Program Data (e.g., WIC, Early Intervention, EPSDT, immunizations, pediatric care, case management, etc.)
Other Child and Family Program Data (e.g., Head Start, school health, special education, etc.)

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were selected to generate meaningful estimates according to major demographic and other factors within states. Currently, states can count on using survey data on a regular basis from the census, the Current Population Survey, and the school-based Youth Risk Behavior Survey. These data sources include information on sociodemographic variables and youth risk behaviors; however, survey information on service utilization variables and insurance status is not available to states on a regular basis unless the state or local area conducts a survey.

The vital statistics birth and death registration systems provide population-based information to state and local communities annually. Although these systems have been used effectively in many states for planning and monitoring of health status, in some states there are still major barriers to providing quality information in a timely fashion to all localities within the state. In addition, the information does not address child health issues beyond the neonatal period.

Surveillance systems and disease registries potentially can be used effectively in planning and in monitoring child health issues. To date, however, these systems have been used primarily for planning and evaluation in a categorical fashion (focusing on one health problem rather than becoming part of an ongoing integrated child health data system used to plan and monitor child health services). In these surveillance systems, as in vital statistics systems, the quality and timeliness of data reporting greatly depends on the resources available within state and local areas.

Finally, program and service management information systems provide another potential source of information about child health and primary care within communities and states. Unfortunately, these systems are rarely population-based and reflect only the outcomes of children in a particular program or system. Although this type of information is often very useful, generalizations from the data to larger population groups are very difficult.

An example from current Massachusetts initiatives may help to illustrate the type of population-based system that is needed and is being developed through the Massachusetts Community Health Information Project (MassCHIP). The overall purpose of MassCHIP is to develop a database for

needs assessment, planning of services, deployment of resources, program evaluation, and monitoring of health status in the Commonwealth. Initially funded through the federal Maternal and Child Health Bureau with Title V funds, MassCHIP will incorporate a wide array of state- and community-level data into a single, comprehensive database system. MassCHIP's menu-driven relational database management system will facilitate numerous types of queries about the data (e.g., by using clusters of geographic areas and varying breakdowns of demographic variables) and will access new data sets and updated data as they become available.

The initial MassCHIP database includes a wide array of health indicators and service utilization data from the 1990 census, vital records and statistics, the Massachusetts Behavioral Risk Factor Surveillance System, uniform hospital discharge data, and the Massachusetts cancer registry. The database also includes program and service utilization data from Title V programs; data from other public health registries or programs related to targeted health indicators such as immunizations, lead poisoning, substance abuse, communicable diseases (HIV/AIDS, sexually transmitted diseases, tuberculosis, vaccine-preventable diseases); and data from other public agency databases, such as data on Medicaid enrollment, child abuse cases, and unemployment.

Without development of a basic MCH population-based data system that operates at all levels of government and serves both consumers and providers, assessing child health status and monitoring the impact of health care systems will remain compromised.

The real potential of MassCHIP will be fulfilled in the future if patient outcome data for the entire primary care system, regardless of payor or type of arrangement, are added to the system. Reform initiatives in some states such as Washington have mandated that all data activities be centralized in one state agency—the health department. MassCHIP provides a model for a population-based data system that can be used to carry out the core functions of public health for all maternal and child primary health care.

CONCLUSION AND RECOMMENDATIONS

Although a number of data sources are currently available at national, state, and local levels, there are significant gaps in the data collected at each level and in the coordination of these population-based sources. Because of these gaps, very little population-based data are available for local and state planning of child health systems. Implementation of an integrated population-based MCH data system for use at local and state levels is possible by enhancing and expanding current data sources.

The following set of recommendations would move the nation toward a population-based child health data system that could be used at local and state levels. These recommendations address two issues: (1) additions to current data sources, and (2) data system development initiatives.

Recommendations for enhancing current data sources:

1. Ensure that each state has an automated birth and death vital statistics system that produces timely and quality data.
2. Add a health services utilization section to the current school-based Youth Risk Behavior Survey.
3. Institute a state-level survey similar to the National Health Interview Survey, with the Child Health Supplement and the Youth Risk Behavior Survey conducted at least every five years or on a rolling basis, so that estimates can be generated in a timely fashion.
4. Develop and implement a national entry-to-kindergarten data registration system.
5. Ensure that race and ethnicity data are collected in a standardized way in all local, state, and federal data collection activities.
6. Ensure that each state has an efficient surveillance system or disease registry, such as a cancer registry or a registry of birth defects, for all health issues. (Although more than half of the states currently have such systems, many states still do not.)
7. Ensure that e-codes (injury codes) are incorporated in all hospital discharge data.

Recommendations for development of data systems to link various data sources:

1. Fund state and local systems to link maternal and child health surveillance and other current population-based data sources.
2. Fund state and local data systems to monitor child health outcomes in primary care arrangements across all payers and communities.
3. Fund initiatives to integrate all child health data sources from surveillance systems, program and service systems, primary care providers, and other sources into a community-based, consumer-friendly "child health report card."

The cost of each set of recommendations should be determined and included in health care reform legislation at the state and national levels. Without development of a basic MCH population-based data system that operates at all levels of government and serves both consumers and providers, assessing child health status and monitoring the impact of health care systems will remain compromised.

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Assessing the Status of Primary Care Services

Early Experiences of the Child and Adolescent Health Policy Center in Evaluating Primary Care

Efforts to move beyond the provision of categorical services will require the public sector to develop new capacities and roles for assuring that the diverse health needs of communities are met. The traditional schism between the public and private sectors in providing personal health services has led to extraordinary fragmentation of services, particularly with regard to the artificial separation of preventive and curative care. Primary care services that provide ongoing preventive care over time with coordinated access to a comprehensive range of services delivered within culturally competent and family-centered environments are a priority in the era of health care reform. This new thrust will direct the provision of services away from specialists toward primary care practitioners as the "hub" or "manager" of the health care of populations.

by
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As states assume greater responsibility and accountability for services within their jurisdictions, they will need tools and procedures, including periodic health status surveys, to assess the health status of communities and to monitor change over time, with special attention to geographic areas and subpopulations at special risk for poor health and/or receipt of inadequate services. Monitoring the quality of primary care will be an essential component in state assurance functions. Information will be needed to guide states in uncovering gaps in services, justifying changes in funding allocations, and identifying potential linkages among providers, resources, and services.

Up to the present, the underdevelopment of a system of primary care has resulted in millions of children lacking access to comprehensive services. As a result, emergency room use for preventable conditions is high and the immunization rates for U.S. children are appallingly low. To avoid continuation of such deplorable phenomena, methods of measuring access to and quality of primary care received by children and of determining the primary care characteristics of various types of health care providers are critically needed.

While some large data sets can be used to demonstrate certain broad-scale needs of specific populations, these data provide a predominantly retrospective and relatively limited view. Strobino[1] and Klerman and Rosenbach[2] exhaustively described the uses and limitations of large data sets, including hospital discharge data, vital statistics, and registries. More refined and specific methods and instruments are needed to document access to services and utilization practices and to provide evidence of emerging needs. Special surveys, used as adjuncts to large data sets, can increase the validity and reliability of information used for planning and resource allocation decisions.

MEASUREMENT OF ATTRIBUTES OF PRIMARY CARE

Supported by the Maternal and Child Health Bureau, The Johns Hopkins University Child and Adolescent Health Policy Center (CAHPC) is developing methods for measuring the attributes of primary care for children. This work includes the development of several instruments designed to describe the characteristics of primary care provided to populations of children. Tools such as these

will help states to identify areas of high need for new services, availability of state and community resources, and changes in service utilization.

Development of the measurement instruments is based on the framework of primary care developed by Dr. Barbara Starfield[3] and further explicated in *Analysis of the Concept of Primary Care for Children and Adolescents*, prepared by The John Hopkins University Child and Adolescent Health Policy Center.[4] This framework comprises seven attributes of primary care: first-contact, longitudinality, comprehensiveness, coordination, community oriented, culturally competent, and family centered. Early work in conceptualizing primary care and systems of health care demonstrated that information from a variety of perspectives would be needed to conduct a thorough assessment of primary care for children within a population. Assessment tools would need to be designed to study the system from four perspectives—the state or agency, the community, the facility or provider, and the client or consumer.

Assessment tools would need to be designed to study the system from four perspectives—the state or agency, the community, the facility or provider, and the client or consumer.

The following sections of this paper describe both the experiences with specific states as they use the attribute framework for strategic planning, and the development and testing of instruments to assess primary care from the four perspectives.

USE OF THE ATTRIBUTES IN STRATEGIC PLANNING: ARIZONA

The Child and Adolescent Health Policy Center framework of primary care was used by the state of Arizona in developing a strategic plan to improve the system of primary care for children in the state. In 1988, the Arizona Department of Health Services conducted a statewide survey of health care utilization.[5] The findings documented the relatively low level of preventive services being received and

the fact that many Arizona families did not have a medical home. In July 1992, the Office of Women's and Children's Health in the Department of Health Services convened the Arizona Children's Primary Health Care Task Force, charged with developing a comprehensive plan that would ensure access to primary health care services for all children from birth to age 21.

Four objectives were delineated for the task force: (1) Define the attributes or characteristics of primary care, (2) determine the criteria for measuring these attributes at both state and local levels, (3) determine how effectively Arizona was implementing these attributes, and (4) develop strategies to improve the system of services. The task force working groups were staffed with central office personnel and a graduate intern from the Department of Maternal and Child Health at The Johns Hopkins University School of Hygiene and Public Health.

The task force worked to develop consensus on key terms for planning such as "systems development," "medical home," and "primary care." Working groups were then formed to determine (1) appropriate roles and responsibilities within a primary health care system, and (2) appropriate policies needed to promote and facilitate a health care home for children and adolescents. Starfield's Health Services System model was then used as the framework to delineate recommendations for system structure and processes (see page 17).

Using an early draft of the Facility/Provider Primary Care Assessment Tool provided by the Child and Adolescent Health Policy Center, a third working group of the task force developed system performance measures for each attribute of primary care. For each attribute, the group determined a "gold standard" and community-level self-assessment questions. Figure 1 illustrates an example of the Arizona approach using the attribute "first-contact care." Planning activities for the implementation phase, which included an in-depth analysis of current system performance, were undertaken in 1993.

This analysis focused on identifying statewide organizational and programmatic policies and procedures influencing access to primary care. This process identified several successful and innovative

Figure 1

Example of Primary Care System Performance Measures Developed by the Arizona Task Force

"First-Contact Care"

Concept: "First-contact care" refers to the primary care provider being responsible for facilitating entry into the health care system [for each nonreferred provision of health care and guiding the client to the most appropriate source of care].

Gold Standard: A system of primary care is established in which the primary care provider is contacted for all health care needs so that an informed judgment is made and guidance is given regarding the most appropriate source of care.

Community-Level Self-Assessment Questions:

1. What mechanisms are in place to encourage individuals/families in the community to contact a health care home for all nonreferred health services? Are these mechanisms documented so that trackable data are available for review?

2. What mechanisms are in place to establish the linkages between the individuals/families and the primary care providers?

Source: Arizona Department of Health Services, Office of Women's and Children's Health. 1994. *A Future for Arizona's Children: Report of the Arizona Children's Primary Health Care Task Force.* Phoenix, AZ: Author.

programs in operation that could benefit from expansion or could serve as models for replication in other sites within the state. However, task force members also identified system inequities throughout Arizona with respect to several "structural" characteristics. Gaps identified in the system include:

> *Poor distribution and supply of primary care providers as well as providers under the Arizona Health Care Cost Containment System (the state Medicaid program), especially in rural areas*—there were 32 federally designated Health Manpower Shortage Areas and 21 federally designated Medically Underserved Areas in the state in 1990.[9]

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- *Inadequate use of facilities in underserved areas due to different service eligibilities*—for example, the Indian Health Service can serve only Native Americans even when other populations live in surrounding areas.[7]
- *Unmet need for linguistically and culturally competent providers especially in predominantly Native American and Hispanic communities*—task force members recognized that the unique cultural composition of Arizona, which includes large populations of Native Americans and Mexican Americans, creates special issues with respect to providing care and receiving care.[8]

Staff in Arizona reported that the CAHPC framework of primary care helped significantly in identifying multiple gaps and insufficiencies in the current system of primary health care services in the state. In addition, the gold standard and self-assessment questions developed through analyzing each of the primary care attributes have provided a sound basis for subsequent activities resulting from the task force planning effort. These activities include various community development projects in which the state maternal and child health (MCH) program becomes a partner with the Arizona Chapter of the American Academy of Pediatrics, private hospitals, universities, and school districts, among others. This experience emphasizes that using a framework to assess the health services system is essential for organizing system components into a context in which they can be understood.

STATE AND COMMUNITY ASSESSMENT OF ORGANIZATIONAL PRACTICES: PENNSYLVANIA, ARIZONA, AND ALABAMA

The state or agency perspective assesses the views and practices of the agencies and programs that deliver and/or assure that primary care services and social support services are available to children and their families. To collect information at the state level, key health policymakers, program planners, and administrators in Pennsylvania were interviewed, using an open-ended, structured interview guide. The approach was not quantitative, but was designed to provide indications of areas needing further assessment.

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Items exploring the domain of first-contact care addressed information that may be symptomatic of a lack of access to primary care services (such as high use of emergency rooms for primary care conditions), the existence of mechanisms to achieve a better distribution of primary care providers across the state, and information on practices to assure that specific populations are receiving primary care services. Longitudinality items explored how families were being encouraged to adopt a regular source of care and described efforts to reduce barriers or provide incentives to receive care from the same provider over time.

The attribute of comprehensiveness was addressed by determining whether the state or relevant agency had specified or recommended a prescribed, or minimum, level of services, and by determining the availability of other primary care-related and support services throughout the state. Finally, the attribute of coordination was assessed by examining efforts to develop tracking systems at the state level to monitor health and health services utilization, and by identifying procedures to make it easier to determine eligibility and to link children and families in need with available programs and services.

State agency and program directors reported that the interview process increased their awareness of the vital aspects of primary care and the importance of monitoring the quality of primary care. Pilot testing of this interview format demonstrated that an enormous amount of information on current organization and past initiatives could be gathered. This method also has the potential to identify duplicative programs and initiatives across different agencies.

The Child and Adolescent Health Policy Center has also used the primary care framework to construct a self-assessment guide to assist communities in examining the status of current local activities undertaken to promote a system of primary care for children and adolescents. The guide can be used by community organizations and agencies (such as task forces, advisory boards, local health departments) to begin a self-assessment for community-based planning. The intent of the guide is to help organize available information and target areas in need of further data on health service resources and public health activities at the community level.

The Arizona MCH program has fielded the self-assessment guide in two areas of Phoenix and Tucson, and now requires applicants for primary care planning grants to complete the self-assessment guide as part of the application process. In addition, Alabama has used the guide (with some adaptations) in all 67 counties within the state as a component of the Title V program's statewide needs assessment. The self-assessment guide will undergo refinement based on evaluation of its use in Alabama and Arizona.

ASSESSMENT OF PROVIDER OR FACILITIES PRACTICES: DELAWARE, DISTRICT OF COLUMBIA, AND WEST VIRGINIA

Early versions of the Facility/Provider Survey were pilot tested in Delaware, the District of Columbia, and West Virginia with the goal of producing data regarding how well primary care attributes were being addressed in a variety of health care settings. As implemented in Delaware, the tool was designed in an open-ended interview format to allow the CAHPC to explore the Delaware responders' understandings of the concept of primary care and subsequently to construct potential items to be used in multiple-choice categories in future versions. In this survey instrument, the attribute of first-contact was assessed through questions concerning the methods used to increase accessibility and availability of services, and mechanisms for obtaining care for families unable to afford care. Longitudinality was ascertained by determining how providers encourage individuals to return to their facility and by determining the percentage of individuals using the facility for both preventive and illness care.

An assessment of the comprehensiveness of services used a checklist to note specific services offered on-site, the source of written standards used, and identification of unmet needs of children and families seen in the practice. For the items addressing the achievement of coordination, responders were asked to identify methods used to assist clients in seeking support services and to assure that information from referral visits is incorporated into an ongoing plan of care.

In determining the level of community-oriented care, the survey asked responders to identify the major health-related characteristics of the community, and to indicate whether they participate in community diagnosis, health surveillance, monitoring, and evaluation. Items addressing culturally competent care asked responders to identify the activities being used to reach culturally diverse populations (such as mechanisms to represent views of these groups in decisions involving policies, priorities, and plans related to the delivery of services). To assess the provision of family-centered care, items addressed the formal and informal opportunities for families to participate in the development of family-centered services and for taking into account the role of the family in the genesis of ill health as well as the response to medical interventions.

At the direction of the Delaware Division of Public Health, 121 providers and facilities were selected for a sample; 82 of these providers were interviewed in person. The sample included a variety of provider sites such as community and migrant health centers, school-based wellness centers, family physicians, pediatricians, and hospital-based primary care clinics. The other major category was designated adjunct health care providers (those providing services mainly to support primary care, such as mental health care and substance abuse treatment and counseling services).

Analysis of the information collected from the interviews indicated distinct strengths in the existing primary care system as well as specific areas for improvement. For example, the "one-stop shopping" approach used to organize services at community centers offered a viable solution to the transportation and scheduling barriers experienced by many families. Representation on community advisory boards—reported by 100 percent of the community health centers and school wellness centers, 86 percent of the public health units, 60 percent of the hospital primary care clinics, and 44 percent of the private physicians in Delaware—was determined to be another area of strength. Areas that were perceived as needing improvement included the lack of 24-hour medical coverage for clients using public health clinics, the lack of knowledge among families about how to access and use the health care system, and poor access to dental care and mental health and psychological services.

A second version of the Facility/Provider Survey was pilot tested in the District of Columbia, using providers and facilities selected randomly from mailing lists provided by the D.C. Commission of Public Health. The attributes of primary care were measured using the same concepts as in the previous pilot studies. The survey was predominantly an open-ended format, with examples provided for clarification and ample space for additional comments. Responders received a packet in the mail that included a full explanation of the survey and a concise narrative on the attributes of primary care.

In the District of Columbia pilot test, the response rate was only 14 percent. Of the total number of responders (*N* = 61), 97 percent were private, for-profit providers, and 3 percent were public, not-for-profit providers. The site of practice was predominantly solo or group practice (59 percent), with the two major practice area designated as pediatrics (56 percent) and general practice or family practice (18 percent).

Early pilot studies indicated the value of developing response options using both open-ended responses and suggestions from reviewers in the field.

In early 1993, the West Virginia MCH program used a multiple choice version of the instrument to survey all providers who might be involved in providing health care to children in the state. Approximately 900 surveys were mailed: 203 to pediatricians, 525 to family physicians, 31 to osteopathic physicians, 82 to community health centers, and 55 to local health departments. With one mailing, an overall response rate of about 20 percent was achieved; 63 percent of responders were pediatricians or family practitioners, 16 percent were community health centers, and about 18 percent were local health departments.

This survey, like the surveys described above, addressed seven attributes of primary care. Data provided the basis for several specific recommendations for program planning. Most notable was the apparent fragmentation of services, with neither private nor public sectors strong in all primary care attributes. The public health arena showed evidence of a high level of knowledge about community

problems, available resources, and interventions. It also offered linkages with enhanced and enabling services. Recommendations to the state included exploring opportunities for bringing the complementary strengths of the different provider sectors together to develop a more coordinated and efficient approach to providing services.

ASSESSMENT OF THE CONSUMER OR CLIENT PERSPECTIVE: DISTRICT OF COLUMBIA

A third area of study was initiated to test an instrument designed to measure access to and quality of primary care received by children. Responses to the items could also be used to determine the relationship between the type of source of care and the primary care orientation of that source. When used in a parallel study of the primary care providers identified by the consumer group, the relationship between the family's perceptions of their child's care and the provider's perception of that care can be ascertained. This information will be useful to planners in their efforts to identify and organize services that better meet the needs of specific populations.

The Consumer/Client Survey is being tested during 1994–95 in a telephone survey of 450 households in a specified area of the District of Columbia. From the outset, this instrument is being constructed according to psychometric principles. Each of the attributes of primary care will be assessed along a scale that will have known internal consistency, reliability, and validity.

The attribute of first-contact is represented by a scale including items developed to measure the level of accessibility and availability of primary care services, satisfaction with various aspects of first-contact, and characteristics of the site of primary care. Longitudinality is assessed by determining the consistency with which the same provider is seen at visits for different health care needs, by the types and locale of services received in the past year, and by the nature of the relationship between

provider and patient. Comprehensiveness is determined by assessing the range of services available at the site of primary care, and the types of topic areas discussed during visits, including child safety and developmental changes.

The extent of coordination is determined by the nature of communication between primary care providers and specialists, assistance received in accessing specialty services, and actions to help families understand and carry out recommendations from the referral visits. In addition to assessing these unique features of primary care, the survey also assesses family centeredness, community orientation, and cultural competency by means of other questions designed to provide scale scores similar to those for the other attributes.

Interviewers recruited by the MCH program in the District of Columbia participated in a two-day training workshop on the use of the tool and telephone survey techniques. The telephone list used to constitute the sample contained randomly chosen numbers (75 percent) and also listed numbers (25 percent) within the survey area.

The telephone interview requires less than 25 minutes for completion, including time allowed to record additional comments offered by the responder. Interviewers report a high level of interest and a willingness to participate when households with children are contacted.

The need to study issues of primary health care for children from the viewpoint of facility or provider was considered the next logical step in collecting the information required to guide the improvement of D.C.'s current "system of care." Thus, the second phase of the project will use a newly developed instrument in a mail survey of the providers of primary care identified by responders of the household survey. Mailing of the survey packets to identified providers is projected for early 1995. The Kaiser Family Foundation will fund psychometric testing of both the Consumer/Client Tool and the Facility/Provider Tool.

CONCLUDING THOUGHTS

Each experience in using the instruments has provided valuable lessons that have been incorporated into further work on primary care assessment. Early pilot studies indicated the value of developing response options using both responses from open-ended versions of the survey and suggestions from reviewers in the field. Review by experts is a critical step used by the study team to develop an instrument that is considered both useful by researchers and pertinent by responders. Pretest administration has indicated considerable face validity for the instruments, which are currently being revised for future administration in different localities.

The pilot studies also increased the study team's concern about the issue of low response with mailed surveys. Creativity in offering incentives for participation and enhancing interest is indicated in this type of study. The use of in-person interviews requires a significant investment in time and staffing resources. This approach, however, reduces the limitations of nonresponse often encountered in mailed surveys. Several other strategies have been identified to increase response rates, including small monetary gratuities to encourage participation, and collaboration with professional organizations to include letters of support and advocacy for the survey project.

This description of recent experiences in developing methods for assessing primary care for children has indicated the tremendous interest among states and localities in undertaking new roles of systems development, accountability, and assurance. Despite the current emphasis on managed care as a possible solution to problems of excess costs and poor primary care, questions about quality of care, health outcomes, or user satisfaction still remain.[9] States and local jurisdictions are approaching assessment and improvement of primary care as critical tasks for improving the health care of children. The Child and Adolescent Health Policy Center will continue to develop and test instruments to assist health care providers and policymakers to collect the information required for rational decision making and sound planning efforts as health care reform evolves.

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Assessing Needs and Monitoring Progress in the Delivery of Primary Care Services for Children and Youth

Programs funded by the Bureau of Primary Health Care (BPHC) provide comprehensive primary care services to the underserved through Community and Migrant Health Centers, Health Care for the Homeless programs, Health Care in Public Housing programs, and primary care programs for persons with HIV infection and for persons who abuse alcohol and other drugs. These BPHC-supported programs consist of more than 700 grantees with more than 1,700 access points. Of the 8 million adults and children served by these programs, approximately 300,000 are high-risk infants younger than one year of age, 1.4 million are children ages 1–11 years, and 800,000 are adolescents ages 12–19 years. In addition, approximately 230 community and migrant health centers operate school-based or school-linked primary health care services programs for children and youth.

by

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Community and migrant health centers offer diverse services, reflecting a broad spectrum of communities. In New York City, for example, urban health centers serve the residents of China Town, the barrios of the Bronx, and Brooklyn's Hasidic community—each presenting different health challenges and requiring individual solutions. Rural centers also meet diverse challenges. A rural center in the Dakotas with fewer than six people per square mile presents a different set of community and health issues than an isolated rural center in West Virginia nestled in the valley where most of the community lives and works. Health centers that serve migrant and seasonal farm workers are beacons for farmworkers harvesting the nation's crops in western, midwestern, and eastern migrant streams.

In fact, Bureau of Primary Health Care programs serve a richly textured nation distinguished by populations of many cultures. Client populations reflect this diversity: 27 percent are African American, 29 percent Hispanic, 2 percent Asian, 38 percent white, 1 percent Native American, and 3 percent other ethnic or racial groups. Sixty-one percent of these persons have incomes below the federal poverty level and are underinsured; 38 percent have no health insurance.

To meet the needs of such diverse and low-income communities, community and migrant health centers must first demonstrate the need for services through a community assessment. By law, the centers must reassess community and user needs periodically, necessitating an assessment of the availability of community resources to meet those needs. Most important, community and migrant health centers are expected to work together with other organizations in the community's health care and social service delivery system to address the needs of populations using these programs.

Many of the Bureau of Primary Health Care's activities relate to the assessment and development of preventive and primary care services for children and youth. By going "where the kids are," school-based health centers surmount a major barrier to health care access, particularly for adolescents.

Through a joint grant program with the Maternal and Child Health Bureau, the Bureau of Primary Health Care has also developed Healthy Schools, Healthy Communities, a comprehensive primary health services program for children and youth that includes a full range of primary care services,

including mental health and social service programs and referral for specialty services such as substance abuse treatment. This program targets homeless children and other children who are at high risk for poor health, school failure, homelessness, and other consequences of poverty. It marks the first time that direct categorical funding has been made available for school-based services in BPHC-funded programs.

Additionally, several of the community and migrant health centers incorporate a pilot implementation project, Guidelines for Adolescent Preventive Services (GAPS), developed by the American Medical Association. GAPS provides systematically developed recommendations for delivering comprehensive adolescent clinical preventive services. The recommendations guide primary care providers in treating physical disease and the medical consequences of adolescent health risk behaviors, and in preventing or modifying these behaviors. GAPS emphasizes that adolescent health care delivery depends on a partnership among parents, adolescents, and primary care providers working together for health promotion and disease prevention.

PARAMETERS OF PRIMARY CARE PLANNING

Using a community-oriented primary care approach, community and migrant health centers deliver comprehensive, family-centered primary care services in all five life cycles (perinatal, pediatric, adolescent, adult, and geriatric). Building effective preventive and primary care delivery systems within this model demands:

- Identifying and defining the target population (e.g., young children and adolescents);
- Assessing the state of health of the population and the factors that have contributed to health status;
- Locating resources within the community to help address recognized health problems;
- Deciding what can realistically be accomplished;
- Implementing and managing delivery systems in response to the identified needs; and
- Evaluating the intervention.

State-based planning is accomplished through BPHC-funded state and regional primary care associations and through cooperative agreements with state health agencies. These associations and agencies assist organizations within their states and regions in development and delivery of comprehensive primary health care service in areas lacking adequate health professionals or among populations lacking access to primary care services.

In cooperation with the U.S. Department of Education, the Bureau of Primary Health Care is identifying communities served by both Chapter 1 schools and by community and migrant health centers. When these schools exist in communities served by community and migrant health centers, the plan calls for (1) bringing the school and health center together for planning, (2) suggesting cooperative initiatives in primary care and health promotion for children and youth, and (3) providing examples of joint planning and implementation activities that succeeded in other areas.

QUALITY IMPROVEMENT

Inherent in the concept of evaluation is the perception of quality. Quality is defined by how well the needs of communities and users are met, by the expectations of the purchasers of care, and by nationally accepted guidelines or standards. For health centers, this operational definition of quality is embedded in the program expectations.

Program Expectations

The initial step of the journey toward quality of care involves defining expectations for an efficiently managed health center that provides quality care. Our expectations are based not only on the laws and regulations governing our programs, but also on the more elusive factors such as identifying and describing the key elements in an effective and successful preventive and primary care program, regardless of government mandate. To accomplish this task, clinical and administrative representatives from health centers met with their counterparts in the Bureau of Primary Health Care to develop Program Expectations for Community and Migrant Health Centers, a document that repre-

sents a consensus of what we mean by a successful, high-quality health center that responds to the needs of its community.

Program Expectations for Community and Migrant Health Centers comprises four major sections: needs assessment and planning, governance, management and finance, and the clinical program. Each section, in turn, contains a core set of expectations followed by necessary explication. These program expectations form the bedrock of the Bureau of Primary Health Care programs and are the source of all BPHC policies—including the Primary Care Effectiveness Review (the instrument used during site review of all BPHC programs every five years).

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Primary Care Effectiveness Review

Like Program Expectations for Community and Migrant Health Centers, the site review instrument was developed with an interdisciplinary team of grantees after close study of related review instruments developed by the Joint Commission on the Accreditation of Hospital Organizations, the Health Plan Employer Data and Information Set, and the Accreditation Association for Ambulatory Health Care. The objectives of the Primary Care Effectiveness Review are to (1) serve as a self-assessment tool, (2) facilitate consultation, (3) recognize strengths that serve as models for others, (4) identify weaknesses that can be improved through technical assistance or training, and (5) monitor the program. Although the review instrument is not an accreditation tool, it is helpful for organizations preparing for accreditation.

The review teams consist of both federal and nonfederal professionals. Most of the nonfederal reviewers are from health centers in other regions of the country, thus facilitating consultation and balance. In addition, all reviewers (federal and nonfederal) must participate in an ongoing training program for reviewers.

The Primary Care Effectiveness Review is a dynamic instrument. Each year, an interdisciplinary group critiques it, assesses the need for change, and revises it accordingly. This 1994 revision focused on new legislative mandates such as case management, lead screening, and key health care developments such as managed care. This year's revision also included a critique and revision of questions, and, most importantly, integration of all Bureau of Primary Health Care service programs into one review document. This means that practices receiving Bureau of Primary Health Care funds for more than one program need only one integrated, comprehensive review. It also means that specific programs such as HIV programs and Health Care for the Homeless review overall primary care issues and that primary care practices, even if they receive no special funding, have the opportunity to review how their practices manage HIV and issues important to homeless families.

The Primary Care Effectiveness Review is based on Program Expectations for Community and Migrant Health Centers and is similar in organizational content, with major sections on administration, governance, clinical issues, fiscal systems, and management information systems. The clinical section focuses on policies and procedures, clinical systems, and clinical services. Notably, all of the sections are interrelated; for example, the results of patient surveys (assessed in the administrative and governance section) are important for clinical care as well as for quality fiscal systems.

Major portions of the clinical section focus on clinical protocols for treatment of common, acute, and chronic diseases (e.g., diabetes, hypertension, HIV, otitis media) in the population served. Medical records are then reviewed to assess use of these protocols by all providers. Additionally, medical records are reviewed for evidence of preventive services. In the pediatric life cycle, records are reviewed to determine use of preventive health schedules and strategies that include anticipatory guidance, growth and development assessment, lead screening, immunization schedules, injury prevention, and oral disease prevention. Records in the adolescent life cycle are reviewed for family planning counseling, immunization schedules, and behavioral risk assessment including diet, exercise, reproductive health, and prevention of sexually transmitted diseases and substance abuse. It is important to note that issues such as confidentiality for adolescents are assessed, as well as strategies used by the practice to identify and manage domestic violence and abuse.

Since each program receives a site visit at least once every five years and about four months before the grant application is due, issues are identified early enough to develop a technical assistance plan to incorporate into the grant application. This approach also means that review of the application is based not on a paper review but on a recent on-site assessment of the practice. After completing over 300 of these reviews as of May 1994, both the BPHC and the grantees think that the Primary Care Effectiveness Review represents a fair balance between monitoring and consultation. In fact, about 25 percent of these reviews have led to requests for some type of technical assistance from BPHC; this does not include grantees who may have sought additional help on their own.

CLINICAL MEASURES

Historically, the health center program had a series of clinical reporting requirements that included immunizations, anemia screening, family planning counseling, hypertension, and follow-up for abnormal Pap tests. Each reporting requirement was based on a medical record review and each had a threshold. For example, the immunization threshold was 90 percent compliance and the standard for follow-up of abnormal Pap tests was 100 percent. Programs that did not meet this threshold experienced consequences affecting their grant funding.

In early 1989, an interdisciplinary group of clinicians and executive directors from health centers met with federal representatives to begin a comprehensive revision of the clinical reporting requirements. For each major life cycle, the group developed a set of measures that were useful both for clinical management and for improvement of community health. These clinical measures include both process and outcome criteria.

The group also reached consensus that clinical outcome measures should:

- Reflect guidelines of professional groups and the *Healthy People 2000* objectives;
- Focus on process and intermediate outcome measures;

- Focus on critical primary care interventions;
- Use the life cycle approach;
- Be acceptable to clinicians and communities;
- Be measurable and realistic; and
- Complement other national health initiatives such as immunization efforts.

In addition to these criteria, the following major assumptions were made:

- Measures are based on community and migrant health center protocols;
- Phase-in time should be included, with opportunities for training and assistance;
- Measures should be linked to community and migrant health center planning and quality improvement activities;
- Measures are user-based, with clinical records as the data source;
- Measures are only indicators, complementing the site review;
- Measures must be viewed within socioeconomic and cultural contexts; and
- Health care provision is still an art—there are many unknowns.

After a comprehensive review of the literature and several work group meetings, the measures were developed and implemented. Since children and adolescents are the focus of this forum, only the pediatric and adolescent life cycles will be addressed. The pediatric life cycle includes assessment for:

- Immunization of infants and children;
- Assessment and management of growth and development problems (growth chart and anemia screen; developmental milestone assessment including gross motor, fine motor, language, and social development); and
- Baby bottle tooth decay prevention counseling (if water supply is not fluoridated).

The adolescent life cycle assessment includes:

- Behavioral risk assessment for substance abuse (including tobacco) in adolescents and in their sexual partners and families; and

- Documented family planning counseling that includes information about prevention of HIV and sexually transmitted diseases.

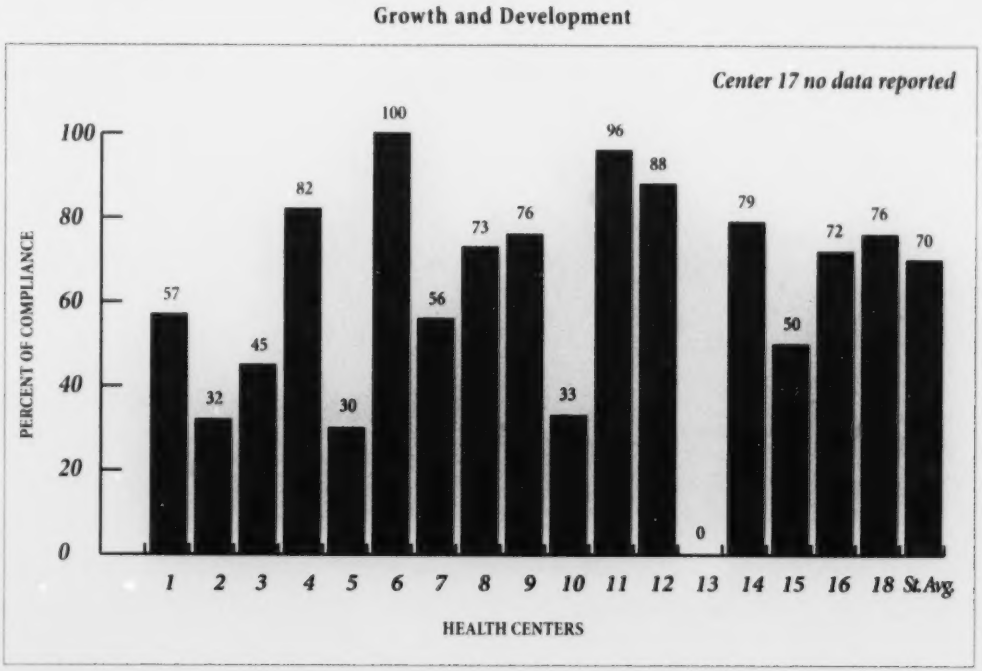
Clinical Measures: Management Philosophy

After a set of measures was established, the next step was to replace the outmoded threshold-punishment approach with a self-management orientation. Consequently, health centers conduct a baseline assessment of these measures and then set a three-year goal. They report their progress toward this goal and request technical assistance if needed. Most important, funding decisions are not based on the baseline measures or the actual goals. Instead, progress toward meeting the health center-generated goals is documented and discussed in yearly progress reports and during the on-site review.

In addition to demanding a more comprehensive look at a specific clinical practice, the clinical measures program also helps to bring health center clinicians together to work collaboratively. Clinicians in several states and regions took the initiative to work together on these measures through their regional or state primary care associations. The Bureau of Primary Health Care supported and encouraged this development not only because is it an effective way to implement the initiative, but also because such teamwork builds clinical excellence at the local level, where leadership in quality belongs and is most effective.

Figures 1 and 2 illustrate how this works. These figures depict a state in which 19 community and migrant health centers are participating in a clinical measures pilot project. In 1993, the centers reported their baseline data around the various measures, and set three-year goals based on these data. Baseline data and yearly progress toward the goals are reported to the network, which reports to the Bureau of Primary Health Care without identifiers. Figure 1 shows baseline levels of compliance for growth and development goals for the pediatric life cycle. Figure 2 indicates baseline compliance levels for assessment of sexual activity during the adolescent life cycle. After establishing these baselines, the centers work together through the network to develop protocols and practice-based strategies for improving baseline levels.

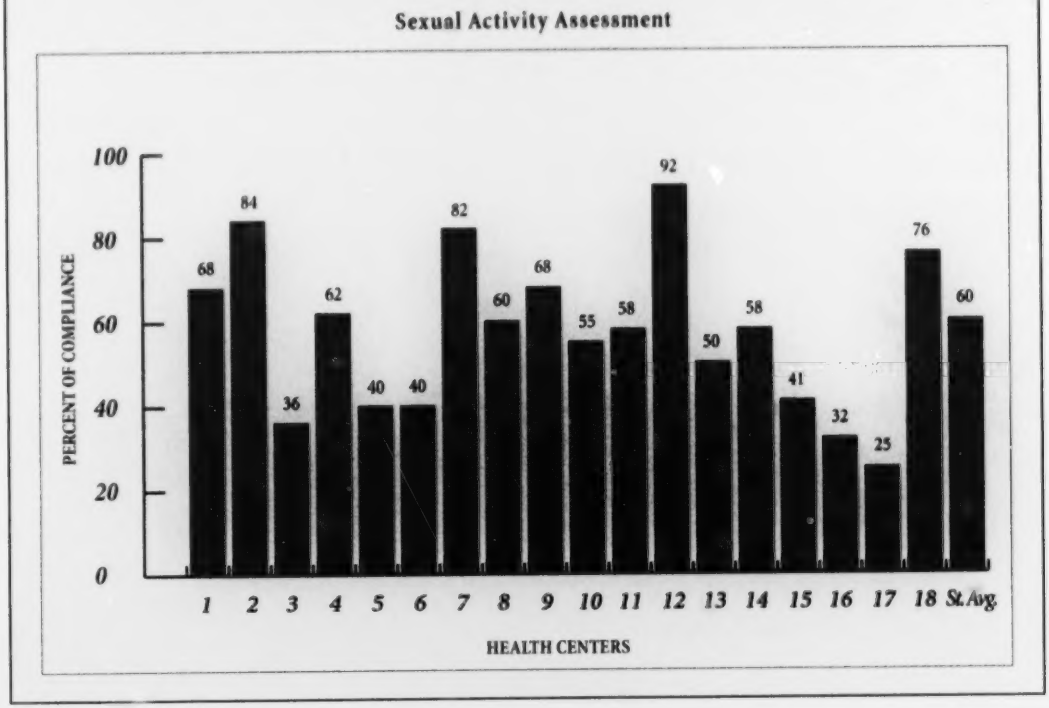
Figure 1-Baseline Clinical Measures



Clinically Useful vs. Statistically Significant

Since the clinical measures program is still in development, it is important to understand that the data are not yet statistically significant. Clearly, random review of even a limited number of records (especially in programs where no medical records are in compliance) can contribute to better care. In addition, the systematic revision of protocols and clinical systems that can result from a limited review is also useful. However, a larger number of charts must be reviewed to achieve statistical significance; on average, 20 medical records were reviewed for growth and development and 26 were reviewed for assessment of adolescent sexual activity. Therefore, the variations noted in the different tables indicates a general idea of some trends, but may or may not be statistically significant.

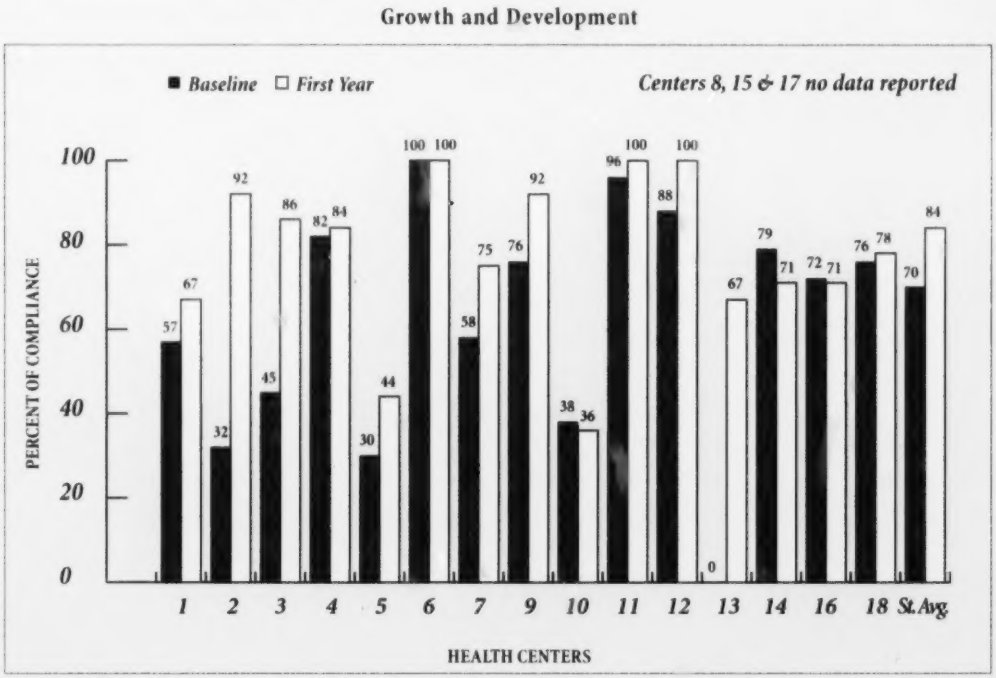
Figure 2-Baseline Clinical Measures



It is also noteworthy that centers were committed to the mission of quality improvement and considered themselves members of a team of health centers. Consequently, they did not hesitate to report, even when no medical records (or a very low percentage) were in compliance.

Figures 3 and 4 illustrate baseline and first-year trend data for both the growth and development and the sexual activity measures. In general, it appears that both high baselines and gains are more difficult to achieve in the care of adolescents than in the growth and development measure for infants and children. Most of the percentages that are within 20–25 points probably represent variation; however, a number of centers exhibited gains of 50 percent or more.

Figure 3-Clinical Measures



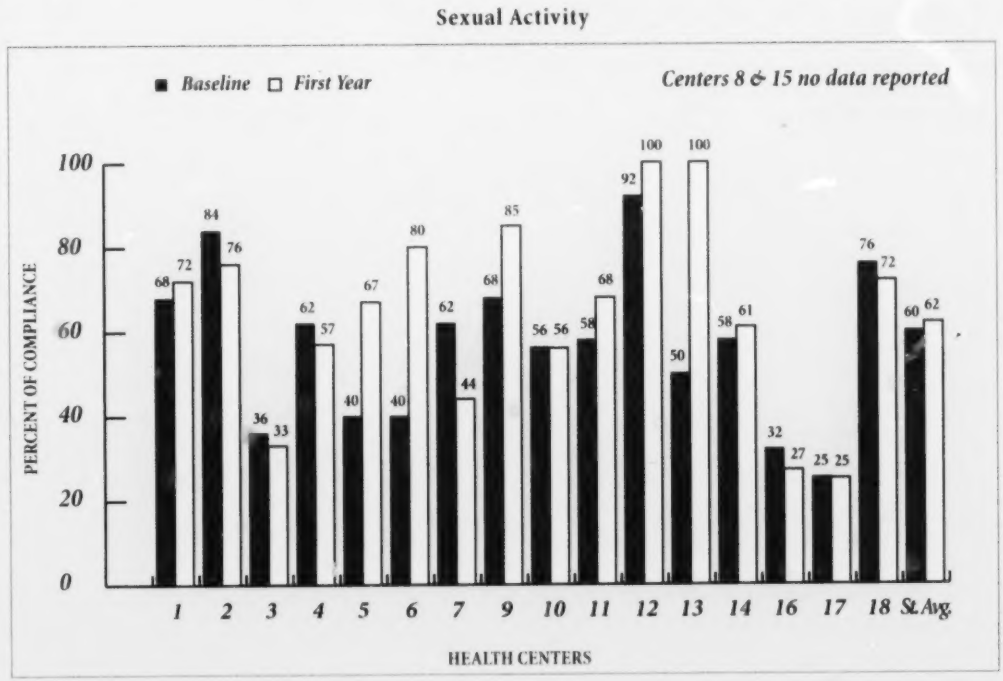
Clinical Measures and Community-Oriented Primary Care

In addition to improving the care of individual patients, the clinical measures also complement the community-oriented primary care approach to community health. The clinical measures help to identify health issues in the target population. The following is an example from a health center located in a frontier area.

Based on the clinical measure for substance abuse, a study of adolescents was conducted using the RAFFT questionnaire for alcohol abuse (see figure 5). Seventy-eight adolescents were screened as

120

Figure 4-Clinical Measures



part of routine athletic health assessments. The investigator was very skeptical that teens would answer the questions honestly and felt he would be wasting his time and perhaps alienating the adolescents in his practice. Instead, he found that teens answered his questions readily. The prevalence of substance abuse among these adolescents is high—as illustrated in Figure 5, with two-thirds of the adolescents responding "yes" to one or more of the questions.

The results also indicated that teens with a family history of substance abuse are more likely to have two or more "yes" answers and that teens have twice the risk of being in trouble if a family member

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Figure 5

RAFFT Screen Responses
Clinic Teens

RAFFT is an acronym for a screening questionnaire

- Do you drink or use drugs to ***Relax,*** feel better about yourself, or to fit in?
- Do you ever drink or use drugs while you are by yourself, ***Alone?***
- Do you or any of your close ***Friends*** drink or use drugs?
- Does a close ***Family*** member have a problem with alcohol or drug use?
- Have you ever gotten into ***Trouble*** from drinking or drug use?

has had problems with drugs or alcohol. The findings show that more teens who have been in trouble because of drugs have two or more "yes" answers and that teens who report that a close friend drinks alcohol or uses drugs have a risk ratio of 19.8 for having two or more "yes" answers. These findings profoundly influenced the study director's clinical practice, and have awakened the community to a problem.

LESSONS LEARNED

Following are some of the lessons learned, especially about the journey to quality in a preventive and primary care delivery system for the underserved and in the context of a community-oriented approach.

Clinicians and staff are enthusiastic if they have:

- Early and continuous involvement;
- Continuous feedback from data;
- Autonomy to solve problems;
- Opportunities to collaborate;
- Opportunities for professional development and growth; and
- Resources available to help them measure and interpret data.

Issues concerning low-income and underserved populations:

- Standards of care are the same as for more affluent populations;
- Target population is highly mobile;
- Poverty is a primary determinant of health outcome;
- Potential exists to learn about community health status;
- Potential exists to improve community health status; and
- Potential exists to document quality for clients.

Issues for primary care organizations to consider:

- Capacity and capability to collect and analyze data;
- Skills needed to improve clinical care;
- Need for networks of community/public health providers;
- Aid in bridging community/administrative/clinical cultures; and
- Need to retain responsibility at the local level and to help develop local leadership to build and maintain quality.

FUTURE DIRECTIONS

Three major issues dominate the immediate future: Managed care, development and use of guidelines, and reintegration of clinical practice with community and public health.

With a population that is defined and identified, managed care has the potential for more effective preventive and primary care interventions. A managed care organization or network committed to community-oriented primary care will view its members as "members for life" and will plan and implement effective health strategies. With such a defined population, assessment of need and health status, effective use of resources, and measurement of impact remain complex, but are now possible.

Access issues such as cultural and language barriers, literacy, and poverty remain, even with a defined group of members. This is especially true for underserved adolescents who are often difficult to find and reach, and for infants and children who depend upon adults for access to both preventive and primary care.

The managed care "report card" or Health Plan Employer Data and Information Set (HEDIS) represents the potential to help measure quality and access as long as indicators that affect health status and indicators that measure cost-effectiveness are chosen. In addition, if HEDIS is viewed only as a "report card" and not as one of many quality improvement tools, the journey toward quality could become a maze devoted to "looking good" rather than improving the quality and impact of health services.

The Bureau of Primary Health Care is enthusiastic about working with the National Committee for Quality Assurance and other committed agencies and organizations during the coming year to integrate the bureau's initiatives (such as the clinical measures) with the HEDIS strategy. In fact, the National Committee for Quality Assurance is now revising HEDIS, with the Public Health Service participating as a partner in this process.

Guidelines

With respect to developing and implementing guidelines, the Bureau of Primary Health Care will continue to consult with organizations developing guidelines and to test these standards in primary care practices in underserved communities. These activities are now under way with the American Medical Association's Guidelines for Adolescent Preventive Services, and the Centers for Disease Control and Prevention's Standards for Childhood Immunizations and hepatitis B guidelines. A similar project is now in the planning stage for the Clinical Preventive Services Recommendations.

In addition to measures, guidelines, and models, clinical practices need resources and expertise to measure outcomes in their practices and to use this information to improve practice and community health impact. Partnerships, however, are crucial to carrying out such a strategy. The Bureau of Primary Health Care is developing models of partnerships between public health agencies, primary care associations, networks of health center clinicians, and clinical practices in order to help busy health center staff review medical records, collect and share community health data, and provide practices with tools needed to use information to improve quality. These partnerships are successful and effective. One state, for example, provides a nurse whose responsibilities are dedicated to these vital quality improvement activities, and this has led to successful implementation of the clinical measures.

In conclusion, the importance of commitment must be emphasized. For people working in community and migrant health centers, in health care programs for the homeless, health care programs in public housing, and HIV programs, their work is more than a job. For many, work within the community health movement helps (along with family and community) to define meaning in their lives. Indeed, a sense of mission and a vision that embraces quality leads to improved health for the future. The planning, the measures, the data, and the technology are secondary. The Bureau of Primary Health Care is committed to such a vision shared with partners in the communities we serve, the people who work to improve the health of underserved communities, and our sister and brother agencies and organizations throughout the nation.

Community System Assessment and Child Health Planning in Iowa

INTRODUCTION

Community primary care planning and development in Iowa arose from concerns about gaps, overlaps, and fragmentation within child health services. In Iowa, the community has been identified as the primary level for intervention; this decision was supported by several observations. The way things get done differs somewhat in each community. Variations arise from many factors, including resources, local history, and culture. At the local level, it is feasible to sort out and weigh the impact of the factors contributing to problems in the local system of care. Collaborating state and federal agencies facilitate and provide resources as localities initiate the process of system change.

by
Charles E. Danielson, M.D., M.P.H., Mary Anderson, M.A., and Kay Leeper, M.S.N.

Primary care has many attributes that can be built upon to address the gaps, overlaps, and fragmentation in local health services. The terms "family centered," "coordinated," "first contact," and "comprehensive" describe a powerful group of characteristics that, when appropriately applied, can exert a positive influence on the behavior of a local health system.

In winter 1991, the Iowa Department of Public Health began working on the Healthy Foundations project, a five-year child health systems development grant supported by the federal Maternal and Child Health Bureau as part of the special projects of regional and national significance (SPRANS). Currently, Healthy Foundations includes 12 projects in 22 of Iowa's 99 counties. The Healthy Foundations project views community primary care enhancement as a leadership partnership between state and local sites, in which issues originate at either level. Healthy Foundations has a continuous quality improvement model for system improvement at the local level guided by a broadly based community coalition. As communities identify, analyze, and improve their local systems of care, they carry out a plan-do-study-act feedback cycle. This paper presents our experiences and identifies key themes that have influenced the success of communities in implementing system changes.

The Healthy Foundations process has been refined over the three years of the project so that much of the community planning is now flexibly guided using a loose-leaf manual (considered a working and evolving document).[1] New projects provide local matching funds of at least 20 percent and receive $5,000 from the state. The community process begins with an application to the Iowa Department of Public Health. The applicant describes the community, the organization, and the initial structure of the community coalition; identifies local resource contributions; and provides assurances that the Healthy Foundations process will be carried out.

A local community coordinator works with community leaders and a Healthy Foundations state consultant to organize or build upon a community coalition. These community coalitions are the keystones of local activity. Each community carries out a facilitated assessment of its child health needs from a primary care perspective, identifying and prioritizing areas for improvement. The community

develops plans to address priority issues, identifies resources, and initiates interventions. Community coalitions continue to monitor the process and either begin new activities or renew their assessments (after a period of time) and continue the cycle.

KEY THEMES

Community

Our approach to communities is based more on functional capacity and patterns of Healthy Foundations than on population size, geography, or government organization. From a primary care perspective, it is important that enough resources exist to support a local primary care system even though the local improvements sought may target only a portion of the community. While this incurs the risk of excluding some small groups, virtually all groups in Iowa are part of a local primary care system, and specific needs can be better addressed within the context of the overall system. Our community coalitions, in aggregate, have a high level of understanding of their community, although individual members or agencies may see some differences. The community is not simply the service area of the administrative agency.

Several problems have arisen, however, in determining how community is defined. A community that is loosely defined and overinclusive can affect the implementation of an intervention. In an effort to improve health services outreach to teens, for example, a local pilot project developed a wallet-size card listing Confidential Health Services for Teens. This local project encompassed several primary care systems.

While exact agreement on community boundaries is not required, wide divergence is problematic. Disagreement over boundaries can affect community investment in the process as well as the success of the pilot project. One coalition is now reaching out to a series of surrounding counties because it views these areas as part of the local service system.

The community's history in working with coalitions and collaborative projects is significant. Past failures can have an immobilizing effect. One community whose history demonstrates strong competitiveness among agencies appears to be slow in progressing. There also appear to be limits in the ability of communities to consider multiple issues. In one Native American community, for example, the Mesquaki tribe casino has been very successful, occupying the attention of the community. This community decided to discontinue the Healthy Foundations pilot project because of difficulties in hiring a local Native American coordinator. The local health leadership was never able to capture the true attention of the elders to develop their local system of care, since they considered other tribal issues more engaging.

It is important for members of a group to define their community. They know who they are and who they serve. In proposing an intervention, they need to consider who will be affected by it. When this impact extends beyond the community, the state leadership attempts to assess the impact on surrounding communities.

Community Coalitions

Although similarities exist in the mix of participants involved in the community coalitions, each coalition reflects the unique aspects of the community it represents. Public health nursing, child health centers, schools, education, child care, and social services are represented in almost all coalitions. Representation from consumers, private business, local government, and private medicine varies, depending on the coalition. Special efforts are made to reach out to consumer and provider groups during the planning process, even when the group is represented in the coalition. The Black Hawk Healthy Foundations pilot project, for example, carried out a consumer survey about immunizations and held physician forums before implementing changes in vaccine distribution.

Each community coalition has a different personality. The nature of each group goes beyond agency representation. Several important factors include leadership, community history, member history, and respect within the community. Increasingly, we view our community development work as more art than science.

Some meetings are very businesslike and other groups have a more casual "down-home" atmosphere. Decatur County, for example, is a rural area along Iowa's border with Missouri; it is one of Iowa's poorer counties, with child poverty affecting 25.6 percent of children in 1990, compared to a state average of 14 percent.[2] The coalition members in Decatur County have a notable tendency to rely on each other; most task agreements are concluded with a sincere "call me if you need help." The common courtesy of calling if a member cannot make a meeting is the rule in the Decatur County coalition. Despite the fact that members already knew each other, the opportunity to come together and examine what they do has been unique. When group members first began meeting, they emphasized how few services were available; after their assessment, they recognized that many services were available and focused on the issue of referrals, especially from private physicians.

System Assessment

Each coalition is responsible for participating in a review of its local health system. The assessment process takes a comprehensive and inclusive look at the primary care system for children. The intent of this process is to identify fundamental areas for improvement. We have found the "area for improvement" framework more useful than the problem approach, since it helps coalition members focus on the system rather than individual health status problems.

It is important for members of a group to define their community. They know who they are and who they serve.

Our state consultants and local coordinators often find that the coalitions have difficulty thinking in terms of system change. Most coalition members have a strong direct care background and are less familiar with system analysis. Focusing on the "problem" often leads to considering a particular condition without giving full attention to contributing factors. Informal training is usually supplied to help distinguish between health conditions and functional areas for system improvement. The area for improvement concept emphasizes building on what works and making it better. In order to achieve this, contributing factors must be analyzed, and both facilitators and barriers must be considered. This approach is more positive and less threatening.

The state supports the assessment process through data—assistance in presentation and interpretation—and group dynamics. The assessment includes indicators of health status, community inventory of services, a consumer survey, analysis of service system characteristics, and targeted community surveys. The state provides core demographic data and health status indicators for the community. Data are generally available for county-based projects. However, in the project addressing Hispanic issues in Polk County, most of the data were unavailable by ethnicity. This experience added momentum to the Iowa Department of Public Health's efforts to collect ethnicity data. The coalitions use project planning materials as a starting point in examining service availability and characteristics of the service.

As Warren Bennis has observed, leadership is about doing the right things, and managing is about doing things right.

The Healthy Foundations project was concerned initially about providing too much data, yet communities sought more. Usually as a community begins to target areas for improvement, additional information specific to the community is obtained. Coalition members' anecdotal knowledge of local situations has commonly steered data gathering. This additional information is targeted to provide specific guidance in implementing an intervention or estimating the extent of a situation. State personnel play a role in facilitating or providing technical assistance in gathering this information.

Coalition Leadership

As often observed, within many groups there are both nominal leaders and "true" leaders. However, the skill and hard work of the local community coordinator is the key factor in the group's success. If the coordinator is unable to devote adequate time (at least one day per week), the coalition moves very slowly. Leadership styles also are important in determining how the group proceeds. If the facilitator has a reactive style, it becomes more important for some component of the group to be proactive. While being proactive is generally viewed as positive, a fine line exists between being proactive and aggressive—"coming on strong" in a community with a history of competitiveness can be counterproductive.

As Warren Bennis has observed, leadership is about doing the right things, and managing is about doing things right.[3] Coalition leadership requires a balance of these two capacities. After defining a problem, it is important to create a shared vision of an improved condition for the community. This skill appears to be separate from the skill of managing the process of "getting there." Some who have created a strong vision have difficulty leading the group to map out a strategy for achieving it. Healthy Foundations attempts to provide specific help, and the project's collaboration with Iowa State Extension and the University of Iowa has proved valuable in this regard.

Family-Centered Care

Member agencies of coalitions have a difficult time balancing agency needs with family needs. As administrators work collaboratively with each other in attempting to strike this balance, difficult decisions must be made to move toward meeting families' needs. Fragmentation in home visiting services is a typical example. In one community, a specific agency has public health nursing funds to provide home visitation for families with infants and children. Expending funds from all agencies involved, however, results in lack of continuity with care providers, as families are moved between agencies to follow the funding stream. An alternative approach calls for the agencies involved to contract all home visiting to one agency. Although the final determination has not been made, this community has a history through Healthy Foundations of tilting the scale toward the needs of families.

The Black Hawk County Immunization Program offers another example of how communities are beginning to succeed in collaborative efforts to provide family-centered care. To immunize children more efficiently, the coalition decided to provide public vaccine to children seen by physicians in private practice, using the "one-stop shopping" concept by allowing families to receive immunizations at the child's medical home. Community resources are joined together collaboratively—hospitals provide courier services to deliver vaccine from the local health department to physicians' offices; physicians complete public forms to account for vaccine usage; and the three local hospitals provide funding for health department personnel to manage the system.

Family-centered care is a simple concept with complex ramifications for the local infrastructure of service providers. Decisions are not always simple. Coalitions, for example, can exert pressure on members or outside groups to move toward more family-centered service delivery; yet coalitions can find it difficult to put aside political issues, turf issues, and funding issues in order to examine a system of care openly and honestly from the family's perspective. A balance can be struck in favor of families, but this can place providers at financial risk since they may need to relinquish funding to another provider. Coalition members in the Healthy Foundations experience have had to take small first steps, build trust, and then take on the harder questions. Some questions remain untouched because they are potentially still too sensitive. We have been most successful in educating local providers about family-centered care; the providers who have internalized the family-centered concept have been the most successful at putting the family first and giving up turf issues. Successes have followed, creating a win-win choice through joining together collaboratively.

IMPLICATIONS FOR STATES

The challenges for states in proceeding along the Healthy Foundations path are significant but manageable. Garnering and maintaining community commitment to improving the local system of care is fundamental—and achievable when states allow communities greater independence in choosing goals and directing activities and resources. Ultimately, system change has an impact on families *at the community level.* Consumers are direct beneficiaries of systems improvements. Although assuring overall direction, basic standards of care, and infrastructure capacity remains an important role for states, communities will become more invested over the longer term when they see progress toward the objectives that they have charted for themselves.

Success is important. It builds enthusiasm and can attract outside attention and resources. Providing technical assistance and changing policy at the state level in response to local-level problems can significantly affect a community's sense of its own capabilities and its ability to influence the larger sys-

tem. Although improving system efficiency and cost-effectiveness is always a goal, allocation of some new resources by states can contribute significantly to the success of community efforts (and result in savings over the long term).

Ultimately, states are challenged to promote partnerships based on tenets of mutual respect and shared recognition of the interdependence of communities and states in working toward the overarching goal—*making systems work for families.*

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Evaluating the Delivery of Pediatric Primary Care in New York City

I would like to share with you some information about our experience in New York City evaluating a pediatric primary care program targeting high-risk children. Medical and Health Research Association (MHRA) administers the Pediatric Resource Centers (PRCs) under contract with the New York City Department of Health, which receives MCH Block Grant funding for this purpose from the New York State Department of Health.

The Pediatric Resource Centers were established in 1985 as a collaborative effort between MHRA and the New York City and New York State health departments. From 1964 until this time, the New York City Children and Youth Projects (funded under Title V) had been providing comprehensive care to many of the city's low-income children. Over the years, however, despite efforts to maintain the

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Children and Youth Projects, funding reductions, the impact of inflation, and significant population shifts culminated in the need for a new approach to distribution of available resources.

Since those resources were no longer adequate to serve the entire population in need (previously served by the Children and Youth Projects) and were clearly insufficient to serve all children in need in New York City, MHRA, in concert with the city and state, forged a program modeled after the Children and Youth Projects but targeting low-income children and adolescents who were at particularly high risk for poor health outcomes, and who lived in high-need health areas. Service priority was accorded to children with certain sociomedical conditions, including children with parenting problems, failure to thrive or significant nutritional problems, or birthweight less than 2,000 grams; and to children who were sheltered/dislocated, children of adolescents, and adolescent parents. Children with birthweights between 2,000 and 2,500 grams, elevated blood lead levels, severe chronic conditions, or other significant medical problems were also eligible for services, but under a second priority. The Pediatric Resource Centers project was envisioned as a means of also strengthening provider links within communities so that care could be delivered in the most rational way possible.

COMPONENTS AND CHARACTERISTICS OF THE PEDIATRIC RESOURCE CENTER MODEL

The service delivery model for the Pediatric Resource Centers consists of six components—availability, accountability, accessibility, continuity, comprehensiveness, and coordination. Health professionals have described many of these elements as essential for providing good primary care, especially for high-risk populations. This approach to the delivery of pediatric services, also referred to as the "medical home," has been promoted by the American Academy of Pediatrics as well as by the Mayor's Commission on the Future of Child Health in New York City.

Currently, eight Pediatric Resource Centers operate at nine sites within outpatient departments of municipal and voluntary hospitals and in freestanding community health centers. Each Pediatric

Resource Center has developed interdisciplinary teams that offer, at a minimum, medical, nursing, social and family support, nutrition, vision, and hearing services. Other diagnostic and treatment services—including mental health, dental, and specialty services and in-hospital care—are available through referrals to each project's parent institution or affiliate. The Pediatric Resource Centers actively reach out to the communities they serve and have established linkages with many other programs serving high-risk children. MHRA has stimulated the development of referral mechanisms between the Pediatric Resource Centers and many of the other programs it administers, most recently with the Infant Health Assessment Program and the Early Intervention Service Coordination Program. These two programs, developed in response to federal mandate, are responsible for identifying and tracking children at risk for or diagnosed with developmental delays, and for assuring that they receive necessary services including primary care.

Total PRC operating costs for 1993 (pending issuance of final expenditure reports) are expected to hover at the $13 million mark, with 40 percent coming from project-generated revenue (e.g., Medicaid, other third-party payments, patient fees), 22 percent from the MCH Block Grant, and 38 percent from applicant support. MCH Block Grant funds are earmarked for uninsured families so as to maximize financial access to enriched services for those children most in need. MCH Block Grant funds are also used to supplement services covered by Medicaid since traditional Medicaid reimbursement does not cover the total cost of comprehensive care.

During 1993, nearly 30,000 patients were seen and more than 100,000 visits were generated. The majority of patients are either African American (52.3 percent) or Latino (34.5 percent) and five years of age or younger (55.9 percent), with males and females equally represented. Medicaid coverage continues to increase, to a great extent as a result of recent expansions in New York State eligibility. The Pediatric Resource Centers have consistently been encouraged to maximize enrollment of eligible patients into the expanded Medicaid program and these efforts have been largely successful, despite limited and often inconvenient Medicaid enrollment procedures. Data from FY 1993 show that 71 percent of the patients are now covered, compared with 45 percent in 1987; 76 percent of the patients reside in high-need health areas and 57 percent are eligible for the program because they have at least one of the highest priority conditions.

FRAMEWORK FOR THE PROCESS EVALUATION

While a number of programs that had been established over the years (including the Children and Youth Projects) incorporated many of the same components later included in the PRC model, their evaluation focused mainly on the process of care. There was some tantalizing evidence from the few that included outcome measures that delivery of comprehensive, continuous primary care services to high-risk children resulted in better patient outcomes than did other kinds of available care, but more definitive studies were clearly needed. Cognizant that this gap in knowledge existed and that lack of sufficient performance data in the Children and Youth Projects had made them more vulnerable to funding reductions, the MHRA Board of Directors wanted to ensure a rigorous and informative evaluation of the PRC program. A two-tiered approach was developed: (1) a process evaluation to confirm the existence of the model; and (2) an outcome study to determine whether the model actually makes a difference in the health and well-being of those receiving services.

The process evaluation, designed by MHRA and the New York City Department of Health, remains in place today (with some minor changes during the years). MHRA annually reviews and analyzes project data collected from four sources: (1) a computerized data reporting system, (2) site visits, (3) chart reviews, and (4) quarterly fiscal reports to determine project-specific compliance with the PRC model. Criteria developed jointly by MHRA, the PRC directors, and the New York City Department of Health are used to interpret much of the information collected. Findings for each Pediatric Resource Center are compiled and then discussed with the PRC directors and their staff at program review meetings. Project strengths and weaknesses are explored and corrective action plans are developed as needed. Progress toward implementing these plans is then monitored during the next year.

Availability and Accountability

The process evaluation addresses all six components of the PRC model. Adherence to program standards for availability and accountability is determined through project reports and site visits. To assess availability, fee structures and policies, appointment systems, waiting time, and after-hours

coverage are reviewed. The model standards require that all patients be provided free preventive services and that families with incomes below the federal poverty level not be charged for any service. Time-specific rather than block appointments are encouraged and waiting time may not exceed 1-1/2 hours. In addition, some form of after-hours coverage with potential for patient contact with an attending pediatrician is required. Accountability is tied to the existence of active quality assurance programs. Over the years, the projects have, on average, done quite well in these areas.

Accessibility

Projects are considered accessible if they are reaching significant proportions of patients who have a Priority I condition, who have low family incomes, and who live in high-need areas of New York City. This information is obtained via the PRC Data Reporting System.

Continuity

Continuity, comprehensiveness, and timeliness of preventive health care are measured through annual chart reviews. During 1993, a random sample of patient charts was selected; these patients were between 9 months and 5 years of age, had begun attending a Pediatric Resource Center within the previous 14 months, and had visited the PRC at least three times for primary care during that period of time. The number of charts averaged 35 per site, but varied depending on the proportion of visits that each site contributed to the total program.

Continuity had been defined during the first year of the program by the PRC Directors, MHRA, and the New York City Department of Health. The indicator that was established aims for each patient to see the same primary care provider at 90 percent of his/her primary care visits. (The primary care provider is defined as the physician or midlevel practitioner providing care at more than half of the patient's primary care visits.) If individual patients are not seen by any one provider at more than 50 percent of their primary care visits, these patients are said not to have a primary care provider. In 1993, continuity ratings ranged from 39 percent to 93 percent, with an average total program rating of 63 percent—five percentage points below that for 1992 but similar to the 1991 finding. Some pro-

jects indicated during the program reviews that a methodology that recognizes a "team" of providers (rather than a single individual) as the primary care provider might be more appropriate, given the high rate of walk-in patients, problems with scheduling patients who see part-time physicians, and difficulty identifying patients' primary care providers. The merits of the team definition are currently under consideration.

Comprehensiveness

Minimum standards of comprehensiveness for the Priority 1 eligibility conditions were also developed at the inception of the program by MHRA, the PRC directors, and New York City Department of Health staff. Three levels of severity were defined for each condition, and, within each of these, a decision was made as to what types of assessments should be required and who should provide them. Based on chart abstract information, the level of compliance is calculated by comparing the total number and type of services and referrals provided to the total number and type required by the standards. Except for a minor decrease in 1990, the PRCs overall have continuously improved in this area, reaching a 79 percent rate of compliance in 1992.

Comprehensiveness was not reviewed in 1993, due to a decision to use the limited resources for expanding the review of preventive health measures that year. Comprehensiveness remains a central component of the PRC model, however, and will continue to be evaluated in the future. The comprehensiveness findings have been useful not only for identifying specific problems within a PRC, but for giving guidance to MHRA in areas where the projects need further support. Findings related to provision of services to families with parenting problems, for example, led MHRA to seek and provide funding to the PRCs for additional staff time and on-site parenting training, resulting in the establishment of discrete parenting programs at each of the sites.

Coordination

The coordination measure has recently been refined to improve its validity. A determination of the projects' internal tracking of hospital admissions, emergency room visits, abnormal laboratory

reports, and subspecialty referrals has been made during the annual site visits and through correspondence with the projects. The degree to which projects follow up on missed appointments is also determined during the chart reviews. The majority of projects have implemented effective mechanisms in these areas although a few have difficulty obtaining consistent feedback on subspecialty referrals. In addition, the chart audit now addresses the extent to which required referrals/consults are actually completed (evidenced by chart notations). This assessment is particularly helpful in identifying gaps between the project's recognition of the need for specific services as reflected by the referral, and the project's ability to ensure that the patient received those services.

In 1992, we began to review a number of preventive health measures that were no longer being tracked, although they were previously assessed by the New York City Department of Health as part of an Early and Periodic Screening, Diagnostic and Treatment/Child Teen Health Plan (EPSDT/CTHP) effort. This review was further expanded in 1993 to include vision, hearing, blood lead level, and tuberculosis screenings along with a determination of patients' immunization status (for diphtheria, tetanus, pertussis; polio; *Haemophilus influenzae* type b; measles, mumps, and rubella). Data on the timeliness of screenings and immunizations administered by the Pediatric Resource Centers were also collected and appropriate interval scores assigned, based on a methodology that accounted for patient status upon presentation to the PRC. Findings were presented so that projects were informed of both the patients' current status and project effectiveness in screening and immunizing those patients once under PRC care. Overall, 81 percent of the required preventive health procedures were carried out.

Projects are also expected to be in compliance with the established productivity standard of 2,800 encounters per full-time physician. This standard, which is significantly lower than that for Community Health Centers, was adopted to allow providers ample time to address adequately the numerous problems of the high-risk children/families targeted by the Pediatric Resource Centers. During the most recent 12-month period for which data are available, the projects somewhat exceeded the standard, reaching an average of nearly 3,000 encounters per provider.

METHODOLOGY FOR STUDYING SERVICE OUTCOMES

This section provides an overview of the methodology used in the PRC Outcome Study and briefly discusses some of its major findings. This research initiative was funded by a number of agencies including the Bureau of Health Care Delivery in the U.S. Department of Health and Human Services, the New York State and New York City health departments, and the William T. Grant Foundation—all of whom recognized the imperative for evaluating the relative effectiveness of a comprehensive pediatric care model. Dr. Jack Elinson was the principal investigator and Ms. Penny Liberatos was the project director.

The main goal of the study was to answer the following questions:

1. Will the health of high-risk, low-income children enrolled in a comprehensive pediatric care program improve over time compared to their health at entry into the program?
2. Will the children enrolled in the model program have better health outcomes than similar children not enrolled in the model program but receiving services in the community?

We were interested in looking at two types of outcomes in general: the extent to which Pediatric Resource Centers succeeded in improving the health of the children, and the extent to which PRCs had an effect on improving the health knowledge and behavior of the mothers.*

To answer these questions, we used a treatment group consisting of children enrolled as patients in Pediatric Resource Centers, and a comparison group that included children equally eligible for enrollment in the PRCs, but who received care from other sources generally available in the community. Three high-risk groups were selected for inclusion in the study: (1) low birthweight infants, (2) children of adolescent parents, and (3) adolescent mothers. (The data collected on the latter group are currently being analyzed and will not be reported here.)

In order to look at changes over time, data were collected on the treatment (PRC) group at two different points approximately one year apart. Data on the comparison children were collected at the later point so that outcomes could be compared. Data collection, which began in October 1987 and concluded in December 1990, included a total of 977 treatment (PRC) group children and 576 comparison group children. The study population was predominantly African American, Caribbean Black, and Latino.

The children in the comparison group were selected for their similarity to those in the treatment (PRC) group in terms of characteristics related to poverty status, risk category, and area of residence. Our information sources included birth certificate registries, child health clinics operated by the local health department, hospital nurseries, and friends of participants. Data were collected through structured interviews with mothers (and occasionally grandmothers or guardians); the interviews included questions about health service utilization; child's health status; child's motor, language, and social development; preventive health behavior; and knowledge and practices with respect to child health care. Interviews were conducted by specially trained bilingual (English-Spanish and English-Creole/French) interviewers who were similar to the respondents in cultural background and age. Medical examinations (including physical health, development, and growth) were conducted by on-site pediatricians who completed data collection forms specifically designed for the study. Laboratory tests, including tests for anemia and blood lead levels, also were conducted.

The importance of provider involvement in the development of methodologies, timely analysis, and feedback to field personnel, and the willingness to reassess and revise approaches, cannot be underestimated.

The study staff developed innovative ways to deal with the many methodological challenges that arose during this demanding field operation. These methods included (1) approaching potential respondents in the clinic waiting room; (2) sending frequent reminders to families about upcoming appointments; (3) preparing all correspondence in three languages; (4) allowing flexibility in choos-

ing a site for an interview, including a family's home or a local coffee shop; (5) reducing the length and bulkiness of the medical form to be completed by physicians; and (6) requesting that physicians fill out the forms at the time of the participants' appointments. Clinical and administrative staff at the involved facilities contributed a high degree of cooperation and input, and the study successfully collected research data from a sizable sample of low-income, inner-city children.

FINDINGS

Outcomes were assessed through nearly 200 variables grouped into seven categories: physical health, psychosocial health, functional health, preventive health behaviors, health knowledge and practices, utilization of health services, and unmet needs for care. First, we analyzed data on the treatment (PRC) children, focusing on changes from time of enrollment to approximately one year after enrollment. We then compared children who used the PRCs for all of their medical care (except emergency room visits) to children who were registered but didn't use the PRC at all over the prior 12 months. Finally, we compared the treatment (PRC) group to the comparison group. Minor demographic differences between the two groups were controlled for in the analyses.

Five outcome categories appear to have been most affected by the PRCs: physical health, preventive health behaviors, unmet needs for care, health knowledge and practices, and functional health.

Of a total of 127 comparisons that were tested for significance between the treatment (PRC) group and the comparison group, 15 percent were found to be statistically significant. Almost 90 percent of these significant differences favored the treatment (PRC) group. Among the more important differences were the following: PRC children were less likely to be delayed in receiving immunizations, less likely to report health problems, and more likely to have received services through the Special Supplemental Nutrition Program for Women, Infants and Children (WIC). Five of

the seven outcome categories appear to have been most affected by the Pediatric Resource Centers: physical health, preventive health behaviors, unmet needs for care, health knowledge and practices, and functional health. The finding that the Pediatric Resource Centers performed better in such important health-related areas as immunization and enrollment in WIC has major implications for well-child care. Actions in modifiable areas of health behavior may have the potential to bring about long-term changes in the more stable physical health status indicators. Mothers' improved health-related behaviors may have a strong impact on the long-term health of their children. The Pediatric Resource Centers' influence on the physical items may not have been as evident because the children were followed for only one year and children in the treatment (PRC) group were very young at the time of enrollment. Clearly, a longer study with a broader age representation is needed.

CONCLUSION

As we approach the 10-year anniversary of the Pediatric Resource Center program, we may conclude that the overall evaluation design has been successful in providing us with relevant and useful data for future program planning. The importance of provider involvement in the development of methodologies, timely analysis, and feedback to field personnel, and the willingness to reassess and revise approaches as needed, cannot be underestimated. This model for evaluating pediatric primary care is unique in its comprehensiveness and its incorporation of difficult measures. Further refinement and possible replication in different settings is our next challenge.

Accountability in Primary Health Care Systems

Conceptual Frameworks and Policy Challenges

The concept of accountability has become a major element of the discourse over health care reform—in part because it appeals to a wide spectrum of political opinion. On the right, accountability implies cost-efficiency; on the left, accountability implies public responsibility. The dictionary definition of accountability contributes to this confusion, listing multiple elements of meaning:[1] Accountability can mean "subject to giving an account—answerable" or "capable of being accounted for—explainable." "Responsible" is a synonym for accountability.

On a less overtly political level, the rationale for focusing on accountability reflects a convergence of several trends in the evolution of the American health care system. On one hand, Americans want to be healthier. Increasingly, the health of the public is viewed as reflecting an orientation

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toward disease prevention and health promotion rather than toward only treatment of disease in medical facilities.[2] Within this framework, the focus of accountability is health outcome or health status. This approach renders health a communal responsibility, where the health behaviors of individuals have consequences for those around them. A good example is childhood immunization—an outcome that has relevance for both personal and communal health. Unless the entire population is immunized, the risk that children will contract communicable diseases persists. Immunization goals are set at the community level, and the system is accountable for these goals.

On the other hand, Americans want their health care to be less expensive. Controlling the cost of health care has become a major, although somewhat elusive, objective of health care reform. Within this framework, the focus of accountability is on providing less costly, more efficient health care services. Providers are being reorganized into "accountable health plans." This approach renders health care providers accountable to the third-party payors for health care services, rather than to the recipients of health care.

Underlying these converging trends is a basic tension between the respective roles of the public and the private sectors. Such tension is an enduring part of the American psyche which holds a basic distrust of government, espousing the ideals of privatization and decentralization. As health care reform progresses, it is no longer clear whether government agencies will be responsible for maintaining public accountability of the health care system or whether mechanisms of the private sector marketplace will be expected to fulfill this function.

This paper strives to synthesize a diverse literature on the concept of accountability and to make it relevant to the development of a primary health care system for children. We intend to explore the domains and locus of accountability, selected issues related to its measurement, and the role of government in emerging health care reforms. In addition, we will apply these concepts throughout to the specific example of ensuring accountability for childhood immunization.

CONCEPTUAL FRAMEWORK: MULTIPLE LAYERS AND DOMAINS OF ACCOUNTABILITY

Much of the debate in health care reform has centered around the proper level of involvement of government in regulating the delivery of health care. Is oversight for the performance of the health care system best assumed by the private sector or by the public sector? In his book *Beyond Privatization: The Tools of Government Action*, Salamon[3] challenges this framework. Salamon believes that the dichotomy between public and private is a simplistic distinction, and, to a large extent, an inaccurate portrayal of the true structure of the public sector. He suggests that a basic transformation has occurred over the past 50 years in the way government services are delivered, so that now government often functions by "remote control." So-called indirect government relies on third parties to deliver services, confining its role to establishing priorities and generating funds. Thus, many government programs are not about direct service delivery by government employees; rather, they embody key features of privatization and decentralization.

To understand these key features, Salamon proposes a framework that analyzes the distinct tools of government action, each with its own characteristics or operating requirements. The key dimensions of these tools include:

- Nature (or mechanism) of the tool. Government may award grants, provide goods and services, or impose regulations to achieve certain goals. To achieve better immunization coverage, for example, a state or county government might contract with private providers, develop provider payment capitation rates that include reimbursement for immunization, attach regulations to reimbursement for Medicaid payments, or legislate vaccination requirements for school entry.
- Structure of the delivery system. Delivery systems may be direct (e.g., Social Security) or indirect. Indirect delivery systems include other entities—public, private business, and private nonprofit—for delivery of public goods such as medical care or legal services for persons of low-income status.

- Degree of centralized control. Categorical grants-in-aid, for example, involve more federal direction than do block grants. A categorical program for administration of immunization services exists, as do stipulations within federal block grant programs (such as the Title V Maternal and Child Health Block Grant program) and preventive health services programs. Similarly, these differing program structures connote varying degrees of specific federal control of immunization-related activities on the part of local and state governments, and the private sector.
- Degree of "automaticity" (i.e., the degree to which tools require detailed and continuous administrative activity to operate). Tax incentives, for example, rely on self-regulatory market mechanisms; in contrast, needs-tested income assistance programs require administrative decision making on a case-by-case basis.

Each of these tools of government has somewhat different implications for implementation and for consequences. Among the important dimensions of these differences are administrative feasibility, effectiveness, political support, efficiency, and equity. The choice of a particular tool of government must be made in light of the intended consequences for the operation of programs. Direct tools, for example, may be easiest to manage but may not yield the greatest degree of effectiveness.

Salamon's work serves to advance our thinking about ways to conceptualize and operationalize accountability. If the concept of accountability is to be useful in understanding health care reform and systems development, we must come to some decisions about *who* will be answerable (*locus* of accountability), *what* will be explainable (*domains* of accountability), and *to whom* the system will be responsible.

Locus of Accountability

The accountable health care entity is called the locus of accountability. Under the concept of "indirect government," public agencies share this basic function with a third (often nonfederal and nonpublic) party. Accountability for immunization coverage for preschool children, for example, may be shared between a county health department (accountable for the total county population) and several health maintenance organizations in that county (accountable for their subscribers). Traditional theories of

public administration, which draw sharp lines between public and private sectors and emphasize hierarchic patterns of authority, will not explain accountability in these situations. Rather, new theories and approaches must emphasize the notions of "bargaining," "persuasion," and "incentives" in a public-private partnership.

Another locus of accountability consists of individual consumers. Using the example of immunization, parents and families are held accountable for the immunization status of their children. This avenue of accountability, involving policies requiring children to be immunized by the time they begin school at age five or six, is very well enforced throughout the country.

Domains of Accountability

The national health care debate of the last few years has crystallized the sharp contrasts in philosophy surrounding the domains of accountability—fiscal, social, political, professional, and outcomes-related. *Fiscal accountability* is probably the most salient of these. Among some of the managed competition plans (market-oriented proposals for health care reform, for example), purchasing cooperatives of employers would be accountable to the member firms (the payers), *not* to government.[4]

If the concept of accountability is to be useful in understanding health care reform and systems development, we must come to some decisions about who will be answerable, what will be explainable, and to whom the system will be responsible.

Kronick argues that "the entity that makes decisions about the volume of funds flowing to health plans [must also be] financially responsible for the implications of its decisions."[5] His argument about accountability relates entirely to the responsibility for assuring that expenditures do not exceed revenues from premiums and that the federal government is not the locus of that responsibility. Alternatively, fiscal accountability mechanisms could be developed (e.g., through reimbursement practices) that reward the provision of care and are consistent with best practices such as the attributes of primary care.[6]

The focus on fiscal accountability contrasts starkly with the *social or moral responsibility* reflected in the statement of Dr. Colleen Kivlahan, Director of the Missouri Department of Health: "In a reformed health care system, all providers must be held accountable for the community's health needs. Families need an integrated health delivery system—starting from a strong population-based public health system, a comprehensive primary health care system and specialty services as needed. Providers of the future must be held accountable for improved health status of families and the communities they serve. Accountability must extend beyond the walls and into the community."[7]

Sharfstein and Sharfstein[8] provide a powerful example of *political accountability* in the health field in a recent paper describing the contributions of the Political Action Committee of the American Medical Association (AMA). Although the American Medical Association officially promulgated positions supporting institution of mandatory waiting periods for handgun purchase and opposing both the "gag rule" and export of tobacco products, AMA's Political Action Committee contributed more money to candidates who opposed AMA's positions.

Professional accountability, widely accepted and practiced, refers to compliance with the sets of standards of care and conduct established for, and largely by, the profession. Thus, the pediatric "red book"[9] sets the standards for primary care providers' immunization practices, regardless of their practice setting.

Outcomes accountability increasingly is being promoted, with continuous quality improvement (CQI) theories and practices becoming operational in business and in government. While grants-in-aid, loan guarantees, and tax expenditures all involve the delivery of financial benefits (issues of fiscal accountability), regulatory programs function by imposing restrictions. The regulatory programs pose a challenge because there is rarely consensus about outcomes desired from a regulation or about the relationship between a given activity or input and the desired outcome. Increasingly, outcomes accountability is becoming a powerful mechanism in driving state, community, agency, and programmatic decision making and resource allocation.[10,11]

Schorr identifies three challenges in this area: (1) developing measures of key outcomes that currently are not being measured appropriately; (2) developing interim outcome measures; and (3) developing indicators of community capacity. Furthermore, challenges center on issues of collective accountability of multiple entities that must work together to achieve those outcomes, as in the case of community immunization levels. In many areas of child health, scientific problems arise in our collective inability to causally link inputs or process to health status or functional outcomes. Fortunately, this is not the case with immunization.

To whom is the system accountable? Is oversight for the performance of the health care system best assumed by the private or the public sector? This question has become increasingly contentious in the national health care reform debate. Traditionally, health care providers have been accountable to government regulatory and funding agencies. Health plans increasingly are being held accountable to employers for the costs and quality of services they provide.

National efforts are under way to develop uniform reporting standards for managed care organizations. The Health Plan Employer Data and Information Set (HEDIS) is a core set of health plan performance measures that may be used as "report cards" on the quality of care provided by competing health plans. The most recent version of HEDIS (Version 2.0) was developed to assist the employer as a purchaser; an adapted version also has been developed for specific use with Medicaid populations. The HEDIS 2.0 quality-of-care measures address public health priorities identified in *Healthy People 2000* and cover a range of health services, including preventive services, acute and chronic illness, and mental health/substance abuse. Childhood immunization is one of the quality-of-care performance measures included in HEDIS 2.0.[12]

The public and private sectors collaborate in various and complex ways in delivering services to communities. The challenge thus lies in finding avenues of accountability under a system of *shared* authority. Applying this approach to the immunization example, Bernier[13] proposes that accountability for population-based immunization rests on collaboration between the private and public sectors. In this specific area, we find examples of joint public- and private-sector development of the

Standards for Pediatric Immunization Practices, endorsed by a wide variety of organizations in the public and private sectors. New national immunization goals of the Centers for Disease Control and Prevention further require consensus identification of the party responsible for immunizing children at the service delivery level, and development of mechanisms to hold these caregivers accountable. Collaboration also is expected on measurement of community immunization rates.

MEASURING ACCOUNTABILITY: FOR WHAT WILL THE SYSTEM BE ACCOUNTABLE?

At the heart of the concept of accountability are issues of measurement. Maintaining accountability is possible only to the extent that standards for health care delivery are acceptable and clear. Moreover, there must be an agreement among the various parties about the establishment and interpretation of measures of accountability. These two areas—setting standards and developing indicators—are discussed in this section of the paper.

Setting Standards

According to Green and Kreuter,[14] standards can be set in several ways: arbitrary, scientific, historical, normative, and compromise. In an excellent example of the utility of these standards, Green and Kreuter illustrate how a combination of the various sources of standards of acceptability were used in the development of the 1990 Objectives for the Nation for disease prevention and health promotion. Scientific standards were developed first, based on extensive reviews of the literature. Historical trends were then examined to project where the country might be in 1990. Next, normative objectives were set, based on the accomplishments of other Western countries that generally fared better than the United States on certain health indicators such as infant mortality. These scientific, historical, and normative standards were submitted to a panel of experts at a national consensus conference to garner agreement on the most appropriate standards. Subsequently, draft objectives for the nation were distributed to several thousand organizations across the country for review. The feedback from this process was consolidated in the U.S. Office of Disease Prevention and Health Promotion publication

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Promoting Health/Preventing Disease: 1990 Objectives for the Nation. The final product, a set of 226 objectives, reflected a combination of scientific, historical, normative, and compromise standards of accountability. A similar process was followed in the formulation of the *Healthy People 2000* objectives. Objective 20.11 calls for national efforts to "Increase immunization levels as follows: Basic immunization series among children under age 2: at least 90 percent."[15]

Development of Indicators

Accountability has been identified as the cornerstone of all financial reporting in government. Hatry and others working under the aegis of the Government Accounting Standards Board have made major progress in conceptualizing and analyzing the various techniques needed to further the science of measuring what they call service efforts and accomplishments (SEA). Hatry defines this as "being obliged to explain one's actions, to justify what one does."[16]

The challenge thus lies in finding avenues of accountability under a system of shared authority.

Historically, annual financial reports are the primary accountability documents made available to the public. Because they generally include little nonfinancial information, they have been criticized for providing insufficient information needed by elected officials, citizens, and other users to assess the results of public agency operations. The need to justify how much money is spent—and how efficiently and effectively it is spent—has spurred efforts to operationalize accountability, such as developing SEA measures in many public service areas including public health.

Under this scheme, measurement of the system's performance involves assessing five areas: (1) structural elements (inputs or health resources), (2) process (intermediate outputs or health services), (3) outcomes (final outputs or health outcomes) and their interrelationships, (4) efficiency and cost-efficiency, and (5) certain explanatory information that enables accurate comparisons of different programs or jurisdictions. The need to measure interrelationships is consistent with the systems approach, which seeks to gather information not only on each component of the system, but also on service outputs and outcomes in relation to inputs.

Hatry defines *input indicators* as "... the amount of resources, either financial or other (especially personnel), that have been used for a specific service or program. Input indicators are ordinarily presented in budget submissions and sometimes external management reports." While health services delivery systems are easily and frequently described in terms of these input indicators, it is worth mentioning that rarely do we account for the adequacy of inputs directed toward the health of children and their mothers. There is reason to believe that these inputs are less than adequate and certainly less adequate than input indicators for other vulnerable groups such as the elderly.

Output indicators are defined as "... units produced or services provided." Among Maternal and Child Health Title V programs, these output indicators (e.g., numbers of children immunized) traditionally have been the only measures of productivity. Unfortunately, they are virtually uninterpretable and unconvincing for accountability purposes when used alone.

Outcome indicators are "... designed to report the results (including quality) of the service." Ironically, in the field of maternal and child health, we have an abundance of outcome indicators—infant mortality rates, childhood immunization coverage, death rates from firearms, and so forth. The SEA approach will help interpret these outcomes and place them in context.

Efficiency (and cost-efficiency) indicators measure "... the cost per unit of output or outcome." In traditional MCH programs at the state and local levels, it has often been difficult to identify the specific costs of specific services because personnel may be performing multiple services at the same time. Even in managed care organizations, it may be difficult to assign the specific cost of a single service such as immunization.

Explanatory information "includes a variety of information about the environment and other factors that might affect an organization's performance on SEA indicators." Because the health status of their jurisdictions is influenced by many factors beyond their control, program managers and program officials, when reporting SEA information, may worry about being unfairly compared and ultimately blamed for findings that are outside their control. Hatry gives the example of variations in weather

conditions for road maintenance. Using the immunization example, the degree to which health insurance policies cover immunization services will vary across the country and will be beyond the control of local officials, but will have a significant impact on the level of vaccine coverage.

Hatry's concept of including explanatory data along with SEA data in public reports is a major contribution to the alleviation of this widespread concern. Hatry et al. argue that selection of an agreed-upon set of explanatory factors permits the examination of changes in these explanatory data over time; consequently, their impact on health status can be more readily and more systematically assessed. Furthermore, prior agreement on a consistent set of explanatory data to be reported in successive years lessens the tendency of agencies to engage in selective reporting because of self-interest. Outcome indicators and payment rates for managed care organizations developed through risk adjustment methodologies might be understood as a reflection of the use and importance of explanatory information.

SEA reporting involves these key questions: What is the level of service accomplishment? And, is the level of service improving, deteriorating, or remaining relatively stable over time? Six major types of comparisons may be made, using examples from the area of childhood immunization.

- Comparison of current SEA information with performance in previous years (examination of trends). An immunization surveillance system can generate immunization coverage rates over specific periods of time.
- Comparisons with similar jurisdictions. An immunization surveillance system can generate immunization coverage rates for specific communities.
- Comparison with technically developed standards or norms. Audits of clinic and provider records are frequently promoted to monitor immunization and other key primary care practices.
- Comparisons of actual SEA with targets or goals set by the agency at the beginning of the year. Use of *Healthy People 2000* objectives at all levels—provider, community, state, and national—exemplifies a way to operationalize this concept.

- Comparison among geographic areas or client groups within the same jurisdiction. As noted earlier, special target objectives for vulnerable subpopulations can (and should) be implemented, along with monitoring strategies, for the *Healthy People 2000* objectives for immunization.
- Comparison of the public sector with similar private sector organizations in terms of costs and results. Ongoing assessments should measure comparative costs and disease rates between (private) office-based clinics, public clinics, and school-based immunization interventions.

IMPLEMENTING ACCOUNTABILITY: INCENTIVES

The well-known story of the measles outbreak in Milwaukee in 1989 and 1990[17] demonstrates the unintended consequences of certain aspects of incentives operating in the health marketplace. In brief, the city experienced an epidemic in which 1,605 children contracted the disease, resulting in 441 hospitalizations and five deaths. A study of the epidemic revealed that most of the cases occurred among Medicaid-eligible children who were enrolled in managed care plans. The plans had received full payment (through capitation) for families, regardless of whether needed services were provided. In fact, these plans had not been aggressively vaccinating children against measles, even though the plans had already been paid to do so!

Incentives in the Private Sector

As noted earlier, however, economic and cultural trends in delivery of and accountability for public goods and services emphasize the use of incentives in public-private partnerships, while simultaneously de-emphasizing regulatory strategies. The "Milwaukee story" demonstrates that appropriate financial incentives, or removal of financial disincentives, to encourage private physicians to immunize all of their patients regardless of insurance coverage might have helped avert a measles outbreak in this city. In England, primary care providers are responsible for immunizing children registered with them. Bonuses are given to primary care providers to increase immunization levels of children

registered in their case load.[18] Some managed care networks have begun to implement similar approaches. A fundamental difference between the British and U.S. systems in this regard, however, lies in the fact that all children in England are assigned a responsible provider, thereby assuring community protection from vaccine-preventable disease.

Incentives for Individual Consumers and Families

Increasingly, individual consumers are being held responsible for their health behaviors; full responsibility placed on providers and plans may entail extensive outreach programming to bring into care those individuals and families who tend to be under-users of the health system. By implementing incentive strategies for consumers, a true provider-consumer partnership is recognized. As noted above, for school-age children, requirements for immunization prior to school entry have been quite effective. However, new approaches are needed for the preschool population. Some states have implemented sanctions, such as withholding Aid to Families with Dependent Children (AFDC) benefits from parents who fail to have their children immunized. More positive approaches can also be used through providing benefit bonuses for public beneficiaries, or through reducing insurance premiums or co-payments for higher income insured families.

Incentives for Collaboration Between Public and Private Sectors at the Community Level

One can envision other scenarios where even broader application of incentive mechanisms might serve to strengthen the system. In the Child Health Investment Partnership (CHIP) in Virginia, for example, the local health department subcontracts with private providers to give care to medically indigent patients. Payment is guaranteed by the public health agency for services provided (regardless of whether a child was previously eligible for Medicaid but is temporarily or permanently disenrolled). The local health department also provides follow-up and other services (such as transportation) to enhance appointment and treatment compliance. As a result, the proportion of children with a medical home in the community has increased along with the immunization rates, and private provider participation and satisfaction with serving low-income families have improved significantly.[19]

CONCLUSIONS

The concept of accountability comes down to elucidating two related issues: Is there a responsibility for the health of a geographic community? If so, who is responsible?

Ultimately, the answers to these questions are a matter of values. In a recent analysis comparing primary health care systems in 10 industrialized countries, Starfield[20] found that, among other characteristics, systems that have "a high societal commitment, as manifested by a government program of services that places a high value on primary care by paying for it and improving access to care," exert a positive influence on the health status of the population. Future efforts to develop accountable systems of primary care can build on the concepts presented in this paper and the examples of the successful application of these concepts in the area of immunization.

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Primary Care Provider and System Challenges in Caring for High-Risk Children and Families

Primary care providers, particularly those in private practice, are likely to face new and expanded roles following health care reform. Some of these changes will be due to increased accountability and responsibility for both the medical and business aspects of health care. Other changes will occur due to expanded eligibility of the population, coupled with the expectation of managed care systems that primary care providers will be open to assignment of patients without regard to social or medical risk. Within this context, tension surrounds a number of issues, the resolution of which will help set the scope and adequacy of the health care system in responding to the needs of children and youth. This paper considers these issues first, then discusses the potentials and challenges of public-private partnerships and the nature and scope of supports that private practi-

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tioners will need to serve increased numbers of high-risk families. The relevance of these issues and the appropriate responses may differ among states and between urban, suburban, and rural areas within states.

ISSUES AFFECTING PRIVATE PHYSICIAN INVOLVEMENT WITH HIGH-RISK FAMILIES

Need for Appropriate Provider Capacity

Nationally, there exists a well-documented absolute deficit of primary care providers. There is a much larger deficit in the number of such providers skilled in responding to the needs of high-risk families and willing to practice in communities where these families are concentrated.

Many physicians in private practice have had exposure to low-income, high-risk families at some point in their careers; for many practitioners, this exposure occurred during their training years in hospital settings which were without adequate resources for this group of families. Although many private practitioners provide care for some Medicaid patients, this patient population is unlikely to include those from high-risk families with multiple problems, who often make heavy demands on a practitioner's time, and may require resources beyond those available through the average private practitioner. Thus, most private practitioners caring for children in the United States have never practiced within an organizational environment effective in managing the needs of high-risk families. In spite of this, many primary care physicians chose their specialty because of their concern for high-risk families and their interest in the problems they present. Given the appropriate supports, such physicians may be interested in caring for high-risk families, though it is unlikely that the country will have an adequate number of these physicians during the next decade.

Few private practices include nurse practitioners and physician assistants, who constitute an additional source of primary care capacity. In contrast, such clinicians often are included in staff model

health maintenance organizations (HMOs). However, these providers constitute a small portion of the total primary care capacity nationally, albeit a resource potentially important in providing care for high-risk families.

Building the adequacy of the nonmedical resources required to meet the needs of high-risk children and youth is of equal importance in managing issues related to primary care capacity. Currently, it is the unusual community that has adequate resources for responding to the needs of high-risk families. Additional resources are needed to provide access to care, such as transportation, translation, and child care services; specialized medical, educational, and social services for children with developmental disabilities or chronic illness; and services for dysfunctional families. If such services are unavailable, even appropriately skilled and motivated primary care clinicians are severely limited in responding appropriately to the needs of high-risk children and youth. Furthermore, these clinicians may become frustrated in their attempts to care for such families and may limit their practice involvement with high-need populations.

Models of Care

Different high-risk families require different types of support. Some families require assistance in recognizing problems experienced by their children and in making basic decisions about their care. Examples of families requiring this level of assistance include youth whose parents have significant mental retardation, overwhelmed single parents, some recent immigrants, and often children within the foster care system. A mother who has been subject to spousal abuse may require a provider who identifies not only her risk, but the risk to her children. In some cases, the provider may need to make basic decisions for an immobilized woman.

Other families, who may be able to identify problems, may have poor understanding of the consequences likely to be involved, and are unable to set priorities or follow through appropriately with action. A third group of families may identify the problems and understand the consequences, but may not be aware of the resources available or how to access them effectively. Some families simply may require information about available resources and encouragement in accessing them. Finally,

some families may be able to manage virtually all needs of their children with only occasional support and assistance during particularly difficult times. These families may need respite services or simply the encouragement and advocacy of the helping professionals involved.

In some families, the level of function is static and unlikely to change; in others, there is potential for growth, as the parents or youth learn requisite life skills, and as parents begin to deal with the problems that impede the care of their children. Ideally, the primary care system will respond to the differing circumstances of families, not only ensuring the appropriate care for the child, but also fostering the improvement of family functioning.

Ideally, the primary care system will respond to the differing circumstances of families, not only ensuring the appropriate care for the child, but also fostering the improvement of family functioning.

With regard to high-need families, the scope of the primary care system's responsibilities and the adequacy of the medical model are interrelated issues. The case manager's level of involvement in outreach, prioritizing, and decision making will vary depending on the needs of the family; in addition, the clinical needs of high-risk families will be diverse, including traditional primary medical care, dental care, developmental disability services, mental health services (including services for substance abuse and behavioral disorders), and preventive services. In order to address other problems effectively, the primary care system may need to respond to family dysfunction as a problem in its own right. Finally, the community in which the child lives may be dysfunctional, requiring the attention of the primary care practice.

In contrast to the diversity of professional services that may be required by high-need families, primary care clinicians, particularly those in private practice, generally follow a medical or biopsychosocial approach in their practice. This approach may be problem-oriented, involving elucidation of the history and objective findings, collection of additional information through testing, obtaining consultation or information from others (including home visitation), and development of a therapeu-

tic plan. Within a setting of continuity, this approach then leads to ongoing monitoring of the plan with changes in therapy as needed. The physician generally relates to families in a collaborative-contractual relationship wherein the physician provides recommendations and the patient or family is free to follow or ignore these recommendations, including return for follow-up. The clinician generally views his or her role as being supportive of the patient, possibly including advocacy in obtaining care through other community agencies. Should a patient not return for follow-up appointments, the private clinician may feel little responsibility for aggressive outreach, and indeed may dismiss families who repeatedly miss appointments.

Such a range of doctor-patient relationships may be too limited for high-need families. Alternatively, adopting the professional relationship modes used by other disciplines may be required to work effectively with some families. Both mental health and substance abuse treatment providers, for example, often must use confrontational tactics with which most primary care clinicians are uncomfortable. Developmental specialists may relate to parents using a developmental model rather than a problem-oriented medical model, and may engage parents as teachers of their children.

A variety of professionals, including those dealing with abusive or neglectful families, use a monitoring and limit-setting style that includes a variety of adverse consequences for noncompliant families. While the primary care clinician may not need to be highly skilled in all of these modes of relating to patients, the clinician nevertheless needs to be comfortable with using them on occasion, and reinforcing their use by other members of the health team.

While high-risk infants or children may be the source of clinical concern, appropriate treatment may need to involve the parents or family rather than the child. In addition to caring for other family members individually, clinicians may determine that, in some cases, interventions are best carried out at the family level. Postpartum depression, substance abuse, deficits in life skills—all are examples where intervention with the mother and/or father may be indicated for high-risk infants. The breadth of the clinician's clinical competencies (including competencies of other team members) will determine the adequacy of response for such families.

In addition to these interpersonal and professional skills, primary care providers working in a high-risk community may need to be conversant with approaches to respond to needs at a population level, including public health, community development and outreach, and social marketing skills. While effective providers do not necessarily need to use these skills directly, they should be familiar with them and support their use by others in the community.

Comprehensiveness versus Compartmentalization: Manager or Caregiver?

The gatekeeper role, particularly within a managed care environment, is becoming one of the core responsibilities of primary care clinicians. Used well, this role can reinforce the primary care principles of coordination, continuity, and comprehensiveness, and can assure access and accountability.

In organizing the care of high-risk families, one approach is to have the primary care clinician (possibly with the resources of a primary care team) assume direct caregiving responsibility for a broad set of clinical needs. An alternative approach is to compartmentalize care, with families referred to various organizational units, as needed. In rural America, family physicians may be "jacks-of-all-trades," providing medical services, arranging social services, and providing mental health counseling as a part of routine practice. Some groups may include a nurse, social worker, dietitian, or other health professionals who work within the same immediate physical space with the physician and share virtually all information and decision making about the families. In this situation, the physician and the other group members maintain a personal sense of responsibility for all aspects of the patient's care. While such teams may be housed within larger group practices or HMOs, the latter often separate functions such as social services, mental health counseling (even for common problems), and nutrition counseling in distinct departments. In such cases, little information may be transferred among providers, decisions may be made by each unit, and the primary care clinician may feel little responsibility beyond the initial decision to refer the patient. Even the case management functions may be removed from the primary care clinician in such organizational arrangements.

Both approaches have their advantages and disadvantages. For many high-risk families, establishment of a single caring relationship that engenders family trust may be critical to accomplishing

long-term adherence to clinical recommendations and achieving behavioral changes. High-risk families often are overwhelmed when meeting with multiple members of a health team and may not be able to respond to the diversity of expectations and priorities. Compartmentalization, on the other hand, may have the advantage of increasing the efficiency, depth, and scope of clinical competencies available to the patient.

Quality, Cost Control, and Cost Shifting

To the extent that quality primary care reduces preventable illness, hospitalization, work loss by parents, and decreased functional potential of children, it may be a highly effective means of cost control. However, within most reimbursement frameworks in the United States, the savings achieved may not result in appropriate support of primary care. To the extent that provision of high-quality comprehensive primary care services is uncoupled from reimbursement and support of primary care, circumstances may be created that "punish" the highly competent clinician, and discourage private physicians from caring for high-risk children and youth.

Primary care providers working in a high-risk community may need to be conversant with approaches to respond to needs at a population level, including public health, community development and outreach, and social marketing skills.

Currently, cost shifting may occur at various levels within managed care systems, perhaps best exemplified by implementation of managed Medicaid programs in various states. The state Medicaid plan may retain financial responsibility for out-of-plan services. The state may shift responsibility and risk for a set of in-plan services to an HMO or other insurance carrier. In turn, the HMO may shift responsibility and risk for a defined set of services to primary care providers. This may directly punish those providers who take on the care of high-need patients. It also places primary care providers in a position to determine the use of resources among all those for which they are directly responsible, those for which the HMO or insurance carrier is responsible, and those for which the state retains responsibility. Acute

and short-term mental health care may be a part of the primary care provider's responsibility, for example, while chronic or inpatient mental health care may be the responsibility of the HMO, and services related to developmental disability may be the responsibility of the state. This type of compartmentalization may lead to suboptimal care decisions.

Depending on accessibility of services and responsibility for emergency room charges, cost shifting may occur among the primary care provider, the plan, the patient's family, and hospitals and their emergency rooms. Similarly, to the extent that prevention is (or is not) carried out adequately, cost shifting may occur between the present and the future.

These reimbursement issues may affect the likelihood that clinicians are willing to care for high-risk children and youth, diagnostic and treatment decisions, the type of relationship established with a high-risk family, and the scope and adequacy of services they receive.

Control and Leadership

In private practice, the physician has been in direct control. Within groups, control may reside with senior partners. Increasingly, private practitioners are complaining that they have lost control of their practice to the managed care industry, insurance carriers, and government regulations. This may be formalized by the selling of a private practice to a managed care company or hospital system. While the Community-Oriented Primary Care (COPC) model and other models of community control exist for federally qualified community health centers, similar patient and community involvement in governance is uncommon in private practice.

The issue of control and ownership not only affects financial and administrative aspects of a practice, but is likely to change the relationship of the primary care clinician and immediate health care team members to outside health professionals and resources, and to patients and their families. A private practitioner may take a high degree of responsibility and personal interest in ensuring an effective and responsive health care organization, while the physician-employee may not. On the other hand, there may be few controls placed on the substandard private physician in contrast to

those placed on the physician-employee. This may be of particular concern for clinicians who operate in relative isolation within a high-need community.

There is no single right or wrong approach in addressing these issues. As a group, the issues will guide the involvement of private clinicians with high-risk children and youth as well as the organization, the location, and the management approaches—and ultimately the adequacy and quality of care provided. In addition, the strategy for one issue will need to interrelate with the strategies for the other issues. Such trade-offs will affect high-risk families and the care they receive. For example, if the physician personally provides a comprehensive scope of services, this will increase the number of primary care providers required for a population and worsen the shortage of primary care providers. The degree to which professionals from multiple disciplines are involved with high-risk families, through either a clinical team or distinct services, will affect the adequacy of response by a physician who is personally limited to the traditional medical model of provision of care.

ORGANIZATION AND MANAGEMENT IN THE PRIVATE SECTOR

A number of options exist regarding the organization of practice in the private sector. These range from the solo physician with a very limited staff to an office-based team with nursing, social service, nutrition, and other professionals who may or may not engage in home visiting and community outreach. Large groups may involve increasingly complex primary care organizational arrangements, including compartmentalization of services and distinct professional units. In addition, any of these organizational entities may engage in various types of linkages and networking with other helping resources in the community. They may have various arrangements with businesses and schools that include part of the patient population they serve. This may result in varying patterns and locations for provision of care, ranging from an office-based setting to home, school, or work settings.

Similarly, a variety of management strategies may be adopted. The physician or other clinician may be both the administrative and clinical manager, or these functions may be separate. Similarly, care

coordination and case management functions may be the responsibility of the clinician, or of a social worker or other health team member. Priority setting and management strategies in a practice may be guided by business interests, a medical perspective, or a community-oriented or community-based perspective.

The primary care provider, though seen as the hub of the medical system, may or may not be the hub of the helping services available to a family. The increasing emergence of the "one-stop shopping" model of helping services may incorporate primary care in a manner that does not allocate to it a central controlling function. For many families, the emerging family center, whether school based or other, may be more clinically effective and cost-effective than medically controlled systems, particularly for high-risk families where the core problems are psychosocial rather than medical.

Potentials and Challenges for Public-Private Partnerships

Societal forces currently are fostering change and innovation in developing public and private partnerships to respond to the needs of high-risk families. Private practitioners are examining their professional relationships and organizational approaches. Many are reconsidering the basic values of their professional lives and the forces motivating the scope of their practice. At the same time, local, state, and federal managed care and health care reform initiatives, including those by private foundations, offer potential for support of innovation and major change in primary care practice.

With good reason, private physicians view health care reform with concern about loss of professional autonomy and control, fearing that they may be unable to respond to the needs of complex high-risk patients due to productivity pressures, reimbursement limits, and disincentives to health service utilization at both primary care and referral levels. At the same time, total health care expenditures in the United States are enormous, and should be adequate to respond effectively to high-need families. Viewed optimistically, current changes may result in primary care clinicians having a greater scope of resources available to them and being more effective in meeting the needs of such families.

If private physicians are to assume a significant role in the care of high-risk children and youth, they will need to develop community linkages and networks and increased information and patient man-

agement capacity. This must occur within an equitable reimbursement framework and within a system that fosters quality of care and accountability over a broad range of outcomes.

Private physicians will require linkages to other caring professionals in the community, including social service, developmental, educational, and mental health professionals responsive to the needs of high-risk children and youth. This should include capacity for home visiting by nursing or social service professionals or paraprofessionals, including assessing the well-being of infants and children in high-risk families. These linkages should connect both ways, allowing easy access to the primary care physician for patients referred from other community agencies (and vice versa).

The data and patient management capacity required should support identification of high-risk children and youth within the community, through a tracking mechanism beginning at birth. It should assure timely and comprehensive assessment and subsequent management of needs, including ongoing monitoring of the resulting care plan. Finally, the data and patient management capacity should serve as an instrument for quality control and accountability, both for the primary care provider and for other agencies involved.

Reimbursement, whether capitated or fee based, must recognize that high-risk families generally require more time during visits, more visits annually, and more after-hours contact, and these encounters generally involve a greater degree of complexity, during individual contacts and over time. To the extent that practices must improve their data and patient management abilities and invest in the effort to establish and maintain required community linkages, they should receive appropriate funding. Time required for these activities is not directly related to the number of visits or patients served and may require substantial investment up front.

Private Practice Involvement: Three Models

At least three models exist for private physician involvement with high-risk children and youth. Basically, they involve different types of linkages between the medical clinician and other required care providers (*see* table, next page).

Developing Primary Care Capacity in Communities

Public-Private Partnership Options

	Linked Traditional Practice	*Activated Practice*	*Fully Activated (COPC) Practice*
Organization	Traditional Solo/Group Practice	Expanded Onsite Clinical Team	Non-traditional Practice; Possible COPC Model
Scope of Services and Model of Care	Medical	Expanded	Comprehensive; Practice Assumes Responsibility for Developing a System of Care within Its Community
Case Management	Separate Entity (Which May Provide Non-medical Services)	Practice Assumes Some or All Case Management Responsibilities	Practice Assumes Most Case Management Functions
Doctor-Patient Relationship	Traditional	Expanded	Most Comprehensive
Case Management Relationship	Separate	Partial Integration	Separate or Integrated
Care Coordination	Physician May or May Not Take Part	Physician Involved, Possible Grouped Appointments	Less Grouping of Appointments Necessary
Care Team Communication	Limited	Increased	High
Case Identification and Enrollment Procedures	Formal	Formal and Informal	Dictated by Clinical Issues
Financial Management	Straightforward	Complex	Less Complex
Potential for Cost Shifting	Great	Considerable	Reduced
Role in Quality Control and Community Development	Little	Increased	Major Responsibility

The first model is the "linked traditional practice." In this model, a physician maintaining a fairly traditional solo or group private practice agrees to work with a distinct entity that assumes coordinating responsibility and possibly provides some or all nonmedical care components. Such units may be based in state departments of health or human services, community health centers, community hospitals, or other community agencies. At a minimum, the private physician agrees to provide primary care services and to be responsive to coordination and tracking activities. The traditional doctor-patient relationship is altered to include formal and informal information sharing with a case manager. Patients may establish their primary relationship with the case manager rather than the physician. The physician's role in needs assessment may be limited to traditional medical assessment, with other areas evaluated independently under the direction of the case manager. The primary care clinician may or may not take part in regular care coordination meetings; however, the clinician does agree to be part of a larger team that is responsible for primary care and related services. Currently, many Child and Adolescent Service System Program (CASSP) groups operate in this manner. The physician's basic responsibility is to identify and care for medical concerns brought by the patient, and to share information with a separate party that assumes responsibility for comprehensive care coordination and provision of nonmedical care. This approach requires specific identification and enrollment of high-risk children and youth in the program. Ideally, identification of families to be enrolled may occur through the physician's practice, the coordinating agency, or referral from other community organizations.

A second model may be termed the "activated practice." In this model, the primary care practice assumes greater responsibility for the high-risk family. This may involve the physician or other clinician assuming some case management responsibilities both for initial assessment and for ongoing care coordination. It may involve on-site or closely linked services by social workers, nutritionists, mental health counselors, or other professionals. These providers may be in the direct employ of the practice or available through contractual arrangements with other community agencies. The practice, for example, may group patient visits during one or two half-days per week when additional staff are present and different scheduling patterns are maintained. In this arrangement, the physician

assumes greater (though not necessarily complete) responsibility for an expanded set of primary care needs of high-risk families. Communication with other team members is increased and is often face to face, rather than through exchange of forms and occasional phone calls. High-risk children and youth are likely to be identified as a separate population for tracking purposes, although the distinction between this group and other patients in the practice may be blurred, with other patients receiving expanded services as needed without full involvement in the practice's high-risk system. Patients who need developmental services or special mental health or substance abuse treatment services may continue to receive them from other agencies, with little involvement beyond referral by the primary care practice.

The third model involves a "fully activated practice" that assumes leadership responsibility for developing a system of care for high-risk children and youth within its community. This generally will require an on-site team of providers skilled in the various disciplines required by the high-risk population to be served. Such practices likely will have many of the characteristics of a fully functional Community-Oriented Primary Care practice. This includes formal mechanisms to identify comprehensively the needs of individual families as well as to assess the needs of the target community and to prioritize and plan an expanded primary care system accordingly. The primary responsibility for care coordination is assumed by the practice, including monitoring the effectiveness of agencies providing specialized developmental, mental health, or other services. In such practices, there may be a continuum of care coordination intensity closely responsive to the ability of the family to manage its own care arrangements. High-risk children and youth may or may not be identified distinctly from other patients (either within or outside the practice).

Of note, within these three models of care, truly high-risk children and youth are likely to receive very similar services because all three systems are likely to include case management and monitoring activities and to involve the efforts of multiple professionals and agencies. Similarly, independently functioning families with parents who are highly competent in managing the health care system and arranging other types of care required by their children also are likely to obtain adequate care in any of these three arrangements. However, a third group of families—who may have a moderate level of

need or episodic need due to temporary parental absence, illness, or other dysfunction—may not be identified as high risk but may still have increased needs. These families are likely to be served quite differently within these three models of care, receiving the best care from the fully activated practice.

Differentiation among these three types of practice is somewhat artificial; each model has multiple variations, so that a continuum among the three is a better description of what is possible. Although a conscientious private physician in the traditional practice model, for example, may take the extra steps to see that individual patients receive adequate care, such a response cannot be considered routinely available to the community for moderate-risk children and youth.

In addition, it is possible that, over time, practices could progress from the first to the third model. A program to develop practices might stage the expansion of a practice's role over time. This might be coupled with needs assessment within the community as well as practice and clinician development. Needed development is likely to include additional training as well as development of systems within the practice and community. This might be supported by philanthropic, managed care, or state funding.

In addition to these models of private practice involvement, similar variations are likely to occur within staff model HMOs. Managed care organizations may create hybrids in which staff model practice units are linked to private practitioners who function following one of the above models, but relate primarily to managed care coordinating staff.

CONCLUSION

Within the rapidly changing health care environment, private practitioners have a number of options through which they may increase their ability to care for high-risk children and youth. Changes toward advanced models of practice may be made incrementally or in major steps. Increased skills, altered models of relating to patients and their families, and assistance from other helping professionals and agencies will be required. Increased data and patient care management capacity and an expanded

model of care and doctor-patient relationships also are likely to be required. Funding these changes may require core support to a practice as well as increased reimbursement per patient for high-risk children and youth. Finally, such changes in practice will best be accomplished if guided by health services research and supported by changes within the professional education of physicians and other helping professionals.

Meeting the Contemporary Needs of Children and Youth with Developing Primary Care Systems

Issues for Pediatricians in Health Care Reform

NEW VISIONS

Meeting the health needs of children and youth requires: (1) universal access to traditional personal health services, both preventive and treatment services; (2) community-wide services, such as fluoridated drinking water and safe playgrounds; and (3) multisystem services to overcome the burdens of poverty, environmental pollution, violence, substance abuse, and inadequate parenting.

Recently, the Maternal and Child Health Bureau of the Health Resources and Services Administration and the Medicaid Bureau of the Health Care Financing Administration convened a panel of experts to develop national guidelines for health supervision of children and youth.

by
Susan Aronson, M.D., F.A.A.P.

Bright Futures: Guidelines for Health Supervision of Infants, Children, and Adolescents details the content of health visits the experts expect will contribute to positive social, developmental, and traditional health outcomes; these services are summarized in table 1.

Today's health care system is poorly equipped to comply with the guidelines presented in Bright Futures. Health services are delivered by a variety of providers in private community-based offices, institutional clinics, and tertiary care practices with or without linkages to primary care providers. Health professionals deliver preventive services in compact units of time intended to achieve comprehensiveness through continuity of family-provider relationships. For the most part, providers expect families to make and keep appointments, respect after-hours arrangements for emergency care, understand or ask for additional explanations, have the resources and commitment to follow instructions, and obtain medications.

The American Academy of Pediatrics' guidelines for routine health supervision distribute the work of anticipatory guidance over frequent visits in a manner similar to *Bright Futures*. The schedule recommends services based on the vulnerable periods in the child's life. Younger children make more frequent visits than older children for preventive and illness care. Frequent preventive visits build relationships between families and health professionals. They also provide opportunities for providers to reinforce parenting skills and give anticipatory guidance to prevent illness and injury. These services particularly benefit families who lack experience in caring for children and who do not receive reliable advice from extended family members. While sick care visits are narrowly focused on the presented problem, they also offer opportunities to monitor and provide missed preventive services such as immunizations.

Table 1

Bright Futures Summary Table (Revised 8/95)

TOPIC	*INFANCY*	*EARLY CHILDHOOD*	*MIDDLE CHILDHOOD*	*ADOLESCENCE*
PERIODICITY	• prenatal • newborn • 1 week • 1 month • 2 months • 4 months • 6 months • 9 months	• 1 year • 15 months • 18 months • 2 years • 3 years • 4 years	• 5 years • 6 years • 8 years • 10 years	• 11 years • 12 years • 13 years • 14 years • 15 years • 16 years • 17 years • 18 years • 19 years • 20 years • 21 years
TRIGGER QUESTIONS	• How are your preparations for the baby going? • Do you have any concerns about breastfeeding? • Have there been any major changes or stresses in your family since your last visit? • Now that your baby can move on her own more, what changes have you made in your home to ensure her safety?	• Does your child have an object or favorite toy he uses to comfort himself? • Does your child have special activities he likes to do with you such as look at a book? • Does anyone in your home have a gun? Is it locked up? Where is the ammunition stored? • Do you feel pressure to toilet train your child? • Are you able to set clear and specific limits for your child?	• How does your child feel about going to school? • What do you do when your child is stressed, angry, or frustrated? **for child:** • Tell me some of the things you're best at. • How are things going at school? • Do you wear a bicycle helmet? • Do you get along with your brothers and sisters? With your parents? • Tell me about your neighborhood. Do you feel safe there?	• How are things going now that your child is a teenager? • What about your teenager makes you most proud? • What are some of the things you do together as a family? How often? **for adolescent:** • Do you have a best friend? Tell me about your best friend. • Tell me how you handle peer pressure. • How is school going? • What do you like to do after school? • Do you have any worries or questions about sex?
DEVELOPMENTAL SURVEILLANCE AND SCHOOL PERFORMANCE	• coos • vocalizes reciprocally • babbles • responds to own name • understands a few words • parents plan for child care needs and secure options • establish relationship with child caregiver • plays interactive games such as peek-a-boo	• imitates vocalizations • expands vocabulary • speaks intelligibly • learns through play and trial and error • has fantasy play and curiosity • parents work with caregivers to better meet the child's developmental needs • foster social, intellectual, and moral growth	• learns alphabet • learns to write • develops verbal and written language skills • increases vocabulary and complexity of thought • synthesizes language, perception, and abstraction • parents promote successful school entry • visit the school • meet and talk to teachers • become involved in school community • review report card	• further develops verbal and written language skills • develops more complex problem solving abilities • parents encourage academic and vocational interests • discuss higher education goals • makes educational, vocational and personal choices • becomes involved in school and community activities

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Table 1 (continued)

Bright Futures Summary Table (Revised 8/95)

TOPIC	*INFANCY*	*EARLY CHILDHOOD*	*MIDDLE CHILDHOOD*	*ADOLESCENCE*
Social-emotional development	• loves and trusts parents • distinctive interactions with different people • stranger anxiety • emerging autonomy • dynamic interaction with toys, other children, siblings, and adults	• emerging sense of self • shows affection, hugs and kisses • sense of gender roles • interacts with other children in play • engages in simple representational play, i.e., dolls, trucks, household tasks • imitates adults • talks about daily activities and experiences at child care, with friends, etc.	• sense of personhood and "fit" • freedom of personal expression • proud of achievements and has sense of self worth and self esteem • moral and spiritual development • good mental health	• emotional separation and individuation • peer relationships • develops strong values • intimate relationships • good mental health • self-confidence • recognition of strengths • stress and conflict management • religious and spiritual needs • new social limits and community roles • reasonable but challenging goals
Physical development	• develops head control • rolls, sits, crawls • grasps, shakes, bangs, throws objects • develops hand-eye coordination • feeds self • pulls to stand, walks • teeth erupt	• walks, runs, climbs, hops • goes up and down stairs • makes circular strokes with crayon • builds block towers, rides tricycle • physical strength, coordination, and dexterity improve • self-care skills emerge, i.e., eating, dressing	• increases strength and motor coordination • participates in individual or team sports and recreation • children with special health needs or chronic illness develop clearer sense of self, increased ability to care for self if appropriate • prepares for puberty • permanent teeth erupt	• increases height and weight to adult level • sexual growth and development • increases strength and motor coordination • participates in individual or team sports and recreation
PHYSICAL EXAM	• head circumference • weight for length • developmental hip dysplasia • muscle tone • evidence of neglect or abuse • red reflex • strabismus • tooth eruption	• height for weight • strabismus • observe feet and gait • caries, baby bottle tooth decay, developmental dental anomalies, malocclusion, or dental injuries • evidence of neglect or abuse	• height for weight and BMI • caries, developmental dental anomalies, malocclusion, gingivitis, pathological conditions, or dental injuries • Tanner stage or SMR • scoliosis • acne • evidence of neglect or abuse	• height for weight and BMI • caries, developmental dental anomalies, malocclusion, gingivitis, pathological conditions, or dental injuries • scoliosis • acne • evidence of neglect or abuse • Tanner stage or SMR • self-esteem, focus on testicular self examination

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Table 1 (continued)

Bright Futures Summary Table (Revised 8/95)

TOPIC	*INFANCY*	*EARLY CHILDHOOD*	*MIDDLE CHILDHOOD*	*ADOLESCENCE*
ADDITIONAL SCREENING PROCEDURES	• metabolic • hemoglobinopathy • hearing • anemia • lead • assess risks: lead exposure, formula, low socioeconomic factors • if risk factors present: hematocrit or hemoglobin, PPD	• vision • hearing • blood pressure • lead • PPD (1 year + upon school entry) • assess risks: lead exposure, hyperlipidemia, low socioeconomic factors • if risk factors present: hematocrit or hemoglobin, annual PPD	• vision • hearing • blood pressure • PPD once before school entry at 4–6 years of age • assess risk: lead exposure, hyperlipidemia, low socioeconomic factors • if risk factors present: annual PPD	• vision • hearing • blood pressure • PPD • if risk factors present or adolescent request hematocrit/hemoglobin, hyperlipidemia, pap smear, syphilis, other STDs, HIV
IMMUNIZATIONS	• HBV #1–#3 • Hib #1–#3 • DTP #1–#3 • OPV #1–#3 • ensure immunization status is up to date	• Hib #4 • DTP #4–#5 • OPV #4 • MMR #1–#2 • Varicella Zoster #1 • ensure immunization status is up to date	**administer once before school entry at four to six years:** • DTP #5 • OPV #4 • MMR #2 • ensure immunization status is up to date	• HBV series if not previously administered • Td booster • ensure immunization status is up to date
ANTICIPATORY GUIDANCE				
HEALTHY HABITS	• cord care • circumcision care • skin, nail, diaper area care • recognize early signs of illness • spitting up • thumbsucking, pacifiers • bowel movements • sleep patterns	• regular play and physical exercise in safe environment • limited television viewing • regular bedtime and adequate sleep • prepare for new siblings • serve a variety of foods • show affection	• healthy family lifestyle • adequate sleep • regular physical activity • limited television viewing • personal care and hygiene • supervised activities with peers • self-discipline • simple household chores	• adequate sleep • exercise at least 3 times per week • conditioning, weight training, weight gain/loss • limited television viewing • personal care and hygiene • household responsibilities
Injury, illness, and violence prevention	• infant car seat • safe cribs, no baby walkers • sleep on back or side • smoke-free environment • smoke detectors • hot water heater at < 120° • avoid excessive sun exposure • avoid foods that can choke • socket plugs, gates • instruction in infant CPR • constant supervision	• toddler car seat • constant supervision • instruction in child CPR • use sunscreen • safety for: stairs, stove, water, home, playground, dog/animal • limit rules for safe behavior • discuss discipline with partner and child caregiver • ensure that guns are locked, ammunition stored separately	• seat belt • teach pedestrian skills • safety for: water, pool, home, bicycle, playground, sports • use sunscreen • rules for: courtesy, safe hallways, interacting with strangers • ensure that guns are locked, ammunition stored separately • prohibit corporal punishment	• seat belt • no alcohol and driving • safety for: home, water, pool • protective sports wear, gear, helmets • no weapons use • skills in negotiation, conflict and anger resolution techniques to protect against physical, emotional, and sexual abuse

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Table 1 (continued)

Bright Futures Summary Table (Revised 8/95)

TOPIC	*INFANCY*	*EARLY CHILDHOOD*	*MIDDLE CHILDHOOD*	*ADOLESCENCE*
Nutrition	• breastfeeding or bottle feeding practices • adequate weight gain • give breastfeeding infants Vit. D • solid foods at 6 months • no cereal in bottle • ensure caregiver is feeding baby appropriately	• family mealtimes • 2-3 snacks per day • offer cup • self-feeding • slower weight gain • ensure that caregiver serves nutritious foods • introduce new foods	• three meals a day • good eating habits with snacks rich in complex carbohydrates • encourage conversation at mealtimes • nutritious school lunch • self-choice of appropriate foods and snacks	• three meals a day • encourage family meals with conversation • variety of healthy foods • nutritious snacks including fruits and vegetables • healthy weight
Oral health	• no bottle in bed or bottle propping • clean teeth • fluoride supplements as recommended	• toothbrushing • no bottle in bed or bottle propping • fluoride supplements as recommended • first dental examination • biannual checkups • prevention of dental injuries	• toothbrushing/flossing • schedule dental appointments • fluoride supplements as recommended • teach child how to handle dental emergencies • permanent teeth and dental sealants	• toothbrushing/flossing • fluoride supplements as recommended • teach adolescent how to handle dental emergencies • biannual dental appointments • no smoking or chewing tobacco
Sexuality		• normal curiosity about body parts and touching • correct terms for genitalia • questions about "where babies come from" • introduce idea that some body areas are private	• picture books on sexuality for family reading • questions answered at an age-appropriate level • review of family life education • preparation for puberty • discussion about STDs and HIV/AIDS	• accurate information about sex • body changes/puberty • sexual feelings • sexual preference and identity • ways to say no to sex • accurate information on birth control and STDs • safer sex
Substance abuse			• counseling about avoiding the use of drugs, tobacco, and alcohol • no smoking or chewing tobacco	• no smoking or chewing tobacco • avoiding drugs/alcohol • avoiding diet pills or steroids • avoid situations where drugs and alcohol are abused • peer counselor to prevent substance abuse

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Table 1 (continued)

Bright Futures Summary Table (Revised 8/95)

TOPIC	*INFANCY*	*EARLY CHILDHOOD*	*MIDDLE CHILDHOOD*	*ADOLESCENCE*
SOCIAL COMPETENCE	• baby's temperament • nurture • play with baby • talk to baby • encourage vocalizations • music • social games • establish bedtime routine • transitional objects at bed time • play with age-appropriate toys • set limits	• praise • encourage language development • modeling appropriate language • initiation and exploration • protective discipline • consistent enforcement of few rules • self-expression and making choices • night fears • socialization with peers • time out and conflict resolution	• family visits to places of interest • encourage peer relationships • set limits and establish consequences • self-discipline and impulse control • respect authority • right and wrong • age-appropriate chores • praise • hobbies • personal space at home • peer pressure • manage anger and teach conflict resolution	• family time • social activities with community groups • team sports • understand parents' limits and consequences • develop strategies for dealing with peer pressure • continue to make independent decisions • recognize consequences for behavior and the rights of others • follow rules • household responsibilities and chores • positive role model • social support systems • new skills
CONSTRUCTIVE FAMILY RELATIONSHIPS	• build support system • build family relationships • preparation for siblings • tiredness and depression • both parents come to health visits • support from partner, family and friends • avoid social isolation • screen unwanted advice • physical/emotional needs of the infant • pay attention to other children in the family	• quiet time for parental couple • affection in the family • individual time with each child • family communication and interaction • toddler's emerging independence • handle conflict between siblings without "taking sides" • play family games • show interest in child care activities	• positive ethical and behavioral role model • praise and respect • foster communication • reasonable expectations • good sibling relationships • handle anger constructively • know child's friends and their families • risk-taking • show interest in school activities	• family members maintain regular interest in activities and concerns • authoritative parenting in democratic style • facilitate independence • limit-challenging behaviors
COMMUNITY INTERACTION	• resources for health care, living expenses • parent education classes • build ties to community • identification of stressors (violence, inadequate housing, poverty)	• resources for health care, living expense • parent-toddler play groups • evaluate child care programs • maintain ties to community • support child care programs • community safety	• resources for health care, living expenses • extracurricular programs • school and community activities • health education • cultural diversity • current and cultural events • social responsibility to make community safe	• resources for health care, living expenses • social, religious, cultural or recreational org. activities • health promotion and disease prevention education activities • current and cultural events • social responsibility to make community safe • college, vocational training or work options • community service

Source: Green M, ed. 1994. *Bright Futures: Guidelines for Health Supervision of Infants, Children, and Adolescents.*

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CURRENT SYSTEM CONSTRAINTS AND CHALLENGES

Provider Compensation

Compensation of providers is determined by patient demand for service, the size of a practitioner's patient panel, and fees for patient care. For salaried providers, these factors determine the salary scale. For fee-for-service practitioners, these factors directly influence take-home income. My discussions with colleagues suggest that, in both compensation systems, productivity expectations and payment mechanisms strongly influence the amount of time spent per patient visit and the frequency of visits.

In 1989, the mean duration of an office visit (sick and well) to a pediatric specialist was 12.6 minutes, with 39 percent of the visits lasting 6–10 minutes, 29 percent of the visits lasting 11–15 minutes, and 16 percent lasting 16–30 minutes.[2] Preventive visits generally take more time than routine sick-child care. In a recent study by the American Academy of Pediatrics, pediatricians reported the length of patient visits for routine preventive care (table 2). If all care and services performed by office personnel are included, pediatricians report the mean duration of a preventive care visit is 24–27 minutes, with the longer visits for teenagers. Of this visit time, pediatricians reported the mean physician time with the child and parent was 16.9–20.3 minutes (table 3). The shortest visits were reported for children between 6 and 11 years of age.[3]

Table 2

Length of an average preventive care visit, including time spent by ancillary personnel

Age of Patients	*Number of Responding Pediatricians*	*Mean Number of Minutes*
Birth to 2 years	665	25.9
3 to 5 years	655	25.0
6 to 11 years	655	24.0
12 to 17 years	656	27.3
18 years or older	414	27.4

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Children under 18 years of age see their doctors often, averaging about 4.2 physician visits per child per year. Children under 5 years of age average 6.7 physician visits per child per year. The frequency of visits by white children is greater than by black children. In 1987, white children averaged 4.6 visits per year compared with 3.0 visits per year for black children. Low-income children, on average, have one less visit per year than middle-income children.[7] With fewer visits for low-income and minority children, more must be accomplished in a single visit.

Table 3

Length of an average preventive care visit, including only time spent by the pediatrician with the child and parents

Age of Patients	*Number of Responding Pediatricians*	*Mean Number of Minutes*
Birth to 2 years	667	18.1
3 to 5 years	661	17.2
6 to 11 years	659	16.9
12 to 17 years	661	20.0
18 years or older	421	20.3

For consumer protection, health care systems and providers should be required to meet quality standards and provide access for children with special health needs. Capitation rates and fees should be adjusted for chronic illness, age, and social and other risk factors, as incentives for accepting patients with complex needs. Without such incentives, effective outreach and comprehensiveness become luxuries, not essentials. Capitation rates and low copayments remove access barriers and discourage provider-initiated overutilization. However, with financial barriers to access removed, health providers need mechanisms to assure that services are not consumed inappropriately, but reach those who truly need care.

Pediatric primary care providers charge relatively lower fees per patient and have proportionately higher overhead costs than providers of adult care. Thus, discounted pediatric fees and capitation

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rates are much closer to office overhead costs than similarly discounted fees paid for adult health care. Pediatric practice is high volume and low margin with little room for economy and increased efficiency. Discounted fees that are barely above cost encourage providers to increase volume and decrease patient contact time to generate enough income for a viable practice. More revenue for primary care is generated from the higher frequency of visits by young children than from visits by older children. Thus, younger children are the life's blood of a pediatric practice.

In 1992, I closed my established private practice to teach and deliver primary care in an academic setting. It was easy to find physicians for families in my practice who paid fee-for-service charges or had infants and toddlers enrolled in a health maintenance organization (HMO). (The HMO capitation for infants is approximately $30–35 per child per month.) However, few practices would accept the families in my practice who had older children only. In HMOs in my area, payment for older children is approximately $8–9 per child per month. And no practitioners wanted my patients with special health needs or my families with complex problems. Some of the children with complex medical or family problems I now see in my academic primary care practice setting should be served closer to their homes, but the doctors in their communities lack sufficient economic incentive to spend the required time with them. These physicians also lack easy access to necessary support services for patient education, coordination of referrals, and patient/family support to care for complex problems.

Management Procedures

Another barrier to providing quality care is the increase in paperwork. Paperwork limits the amount of time available for interaction between families and health professionals during a patient visit. In my current practice, the schedule allots 15 minutes for the typical well-child visit of an established patient. In this time, I must perform and document the patient's history, the physical examination, and my anticipatory guidance in the medical record.

I must also obtain signed consent forms for immunizations, and complete a series of other forms. These include an encounter form to enter diagnosis and billing information; an order form for laboratory tests; a form for recording the findings of the examination for the Early and Periodic Screening, Diagnostic and Treatment (EPSDT) program under Medicaid (or a separate encounter form if the patient is a member of an HMO); a form to qualify the patient for the Special Supplemental Nutrition Program for Women, Infants and Children (WIC); a report of the child's health status for the early childhood education records, school, or sports program; a parent-held immunization record; and, if the child is in foster care, a separate report to the foster care agency. If the child needs special care, I must complete a form for each referral. In The Children's Hospital of Philadelphia, medical records are not always accessible, so I also keep notes on a "shadow" record for reference at my desk when I have a patient encounter without the chart. Documentation alone takes at least 15 minutes for each patient.

Each telephone encounter is documented using protocols that help assure quality and protection in the event of a lawsuit. Federal law requires extensive documentation for simple in-office laboratory services (Clinical Laboratory Improvement Act), control measures for blood-borne pathogens (Occupational Safety and Health Administration), and evidence that services are not being denied to employees or consumers with disabilities (Americans with Disabilities Act). Independent practitioners must keep these records or risk fines. Each third-party payor has a different encounter form and discounted fee schedule. Anxiety over exposure to medical liability requires time-consuming excessive documentation and medically unnecessary services "just in case" a decision is questioned. In every setting, these factors increase overhead costs.

Patient Expectations and Health Services Needs and Utilization

Medicaid expansion and improvements in Medicaid fees have made a difference in access to care for low-income families. With Medicaid expansions, the number of children added to the Medicaid program increased nationally by 36 percent between 1991 and 1992. In Pennsylvania, that number

increased by more than 53 percent.[6,7] The American Academy of Pediatrics plans to publish data that show an increase in pediatrician participation in Medicaid and an increase in patient load covered by Medicaid since these expansions. Expanded Medicaid coverage and increased Medicaid fees can bring more low-income patients into private practice settings.

Many practitioners feel they have few incentives to welcome and work with low-income families. Medicaid is often associated with increased paperwork, low fees, and delayed payments. Waiting and examination rooms are jammed when families bring all their children to every visit because they do not have or cannot pay for alternative child care. Some low-income children have unmet medical needs for preventive health care and chronic health problems. Low-income patients more often miss appointments or come late because of transportation and other problems. In the Primary Pediatric Practice at The Children's Hospital of Philadelphia, the no-show rate is 40 percent; this can be reduced to 30 percent only by attempting to call every family the day before the visit. The on-time arrival and no-show rates fluctuate widely. Compensatory overbooking often results in long waiting times.

Health providers must modify service delivery to respond to consumer behavior. More low-income families use after-hours care because they cannot take time off from work without losing their jobs, or because of poor planning. More low-income patients do not seek and use telephone advice for illness appropriately, fail to comply with instructions to follow up by phone, and do not follow care plans because they do not understand them or do not have the resources to comply. Some forget to bring their insurance information to each visit, or to do what is necessary to keep their insurance coverage current. Health professionals have a hard time contacting those families who lose their phone service and change their address when they cannot pay their bills.

Primary care practitioners lack the tools to address the causes of many health problems. Poverty, single-parent families, teenage parents, dysfunctional families, injuries, environmental poisons, substance abuse, irresponsible sexual activity, and chronic and incurable disease increasingly threaten the health of pediatric patients. Poverty must be addressed through education, housing, and job

opportunities. Risk-taking behavior and removal of environmental hazards require social and political action. Physicians need education, time, and compensation to collaborate with other community professionals as members of a team working together to help solve these problems.

To serve families with complex needs, physicians must work with home health agencies, educators, and social service agencies. Case management and care coordination take time outside the usual practice schedule. Currently, practitioners squeeze in telephone contacts with other agencies before, after, and in-between patient visits. Few physicians have time to attend interdisciplinary meetings to coordinate medical care with other services required by their patients. In settings that provide care for many patients with complex needs, a care coordinator may be hired to represent the medical practice in such activities.

Armed with special credibility in our society, physicians can advocate for their patients in service systems and seek social and political change in their communities. However, advocacy activities also take time away from the practice schedule. Compensation for out-of-office work is unusual. Expanding expectations for the role of practitioners add to the stress of health professionals who struggle to serve families competently.

Some physicians have adapted to practice pressures by making more efficient use of patient contact time. As many services as possible are provided by ancillary personnel before and after the health provider encounter. Many offices now gather data through self-administered forms and provide information through handouts. However, self-administered forms and handouts are not suitable for families with low literacy levels or those who bring multiple children who demand continuous attention from parents.

Health care reformers must address the similarities and differences in the objectives of consumers and providers in the health service relationship (Table 4). Where there are differences, the system must make accommodations and educate consumers and providers about the ultimate value of the

Table 4

What Families and Providers Want from Primary Care

	Unique Objectives	*Common Objectives*
Families	service on demand, personal care; pleasant experiences; convenient location; convenient hours; competent care; reassurance	continuity of care (relationships); low or no charge at point of service; little hassle from deductibles, coinsurance/payments; little paperwork hassle
Primary Care Providers	reasonably predictable work schedule; confidence in own competence; autonomy, power, control of work; good income and lifestyle; status and community roles	

compromise to them. The cost-containment imperative is insufficient rationale to cover all patient/provider accommodations.

THE POTENTIAL AND CHALLENGES IN DEVELOPING COMPREHENSIVE SYSTEMS OF CARE

The debate over health care reform is shaping public policy and allocation of public resources. As many voices as possible must call for adequate resources and accountable systems to meet the needs of children and youth. Health care reform must expand access to primary care and reduce unnecessary administrative burdens on families and practitioners. The focus of care must return to serving the child and family, instead of serving the system of care. More primary care providers must be lured by incentives to work in medically underserved rural and inner-city areas, not coerced by threatened sanctions or the need to relieve heavy debts acquired during their education.

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Expanding Capacity with Midlevel Practitioners

While Medicaid has increased access for harder-to-serve families, in many states, this financing system preserves a two-class system of care through deeply discounted compensation. Some suggest that a large cadre of midlevel practitioners should be educated to provide primary care for families in traditionally underserved areas at lower cost than physician care. How will midlevel practitioners give sufficient care to populations with high need and chronic medical problems? Midlevel practitioners lack the rigorous education of physicians. In my experience, few midlevel practitioners are willing to work extended hours. How will service by midlevel practitioners achieve positive health outcomes and cost savings?

I have worked with and been preceptor for pediatric nurse practitioners and physician assistants in both inner-city and suburban practice settings. While midlevel practitioners often spend more time with families and improve patient satisfaction, they do not necessarily reduce the cost of care. At The Children's Hospital of Philadelphia, after a period of employing pediatric nurse practitioners, the Primary Pediatric Practice returned to recruiting only pediatricians. On balance, the added cost of physician time required to supervise the patient care of nurse practitioners, the assumption of medical liability for the nurse practitioner's work by the supervising physician, the extended working hours accepted by physicians, and the high market rate for compensation of nurse practitioners made hiring physicians a better buy.

The focus of care must return to serving the child and family, instead of serving the system of care.

Incentives for Quality and Innovations in Service Delivery

Health care reformers must resolve the conflict between resource limitations and approaches required to provide comprehensive care for children. To improve their efficiency and effectiveness, health providers must have the resources to invest in the development and installation of new technology such as computer tracking and management information systems. Despite the lack of data showing cost-effectiveness, payors and providers must agree to some set of fairly compensated preventive services. Once the service goals are set, health care reformers should develop incentives for

quality and innovation in service delivery. Some managed care systems already provide financial incentives for quality indicators such as medical record documentation, immunization completeness, no-show outreach, and extended office hours. The rewards must be prompt and substantial to make a difference. In Great Britain, for example, physicians are paid a bonus of 5 percent of their annual compensation for achieving complete immunization for 90 percent of their patient panel.[7]

Public Health and Pediatricians' Roles and Partnerships for Meeting Population Needs

In addition to individual practices, many pediatricians already are involved in new roles as practitioners of community pediatrics. F. Edwards Rushton, director of the Office of Community Pediatrics of the American Academy of Pediatrics, defines community pediatrics as "a body of clinical skills that allows a pediatrician to diagnose health services needed by children in the community and to use community resources, including people and institutions, to respond to those needs." Child health providers need special training in how to view and serve the community as another type of patient. The payback for altruistic physicians who undertake this work as a sideline to their practice is substantial: increased self-esteem, improved effectiveness in caring for families with complex problems, and practice-building associated with increased credibility in the community. While we applaud these dedicated pediatricians, their work as practitioners of community pediatrics can supplement, but cannot replace, systematic community health planning and allocation of resources.

The need for practitioners of public health has never been more acute. To provide effective service to the community, how can public health link with private practice? First, we need consensus on objectives of health service delivery. We cannot expect to deliver all services in the practitioner's office. Some will be more effectively delivered in settings such as child care, schools, or the home. These services must be organized and delivered without fragmenting or duplicating health care. Continuity of family-provider relationships is essential to quality care.

Health care planners need to have surveillance data collected by public health agencies. By monitoring unmet needs and the effectiveness of interventions, public health professionals can direct efficient use of scarce health resources. Private practitioners must be involved in setting community

objectives, too, so that their efforts can be harnessed to achieve health objectives. Public health and private practitioners must work together to weave a seamless web of service for children. For example, we can target and fund a pool of social workers, nutritionists, and mental health professionals to serve high-risk families such as single and teen parents, and families at risk who are identified by any provider in the community. In addition, public health professionals must assure regional availability of specialty services for those uncommon medical problems that no one health provider could be expected to handle competently alone.

Public health professionals should provide services that are delivered more efficiently and effectively at the community level than at the level of the individual provider. In addition to the pool of social, nutritional, and mental health services for practitioner referrals, public health authorities should organize communitywide programs for environmental health (surveillance and technical assistance for group care facilities, food handling, pest control, lead screening and abatement), mental health (disaster management), nutrition programs (WIC), oral health (fluoridation of drinking water), health education (smoking cessation, responsible sexual behavior), and prevention via regulation (immunization for school, seat restraints, bike helmets, smoking bans in public facilities, licensure of facilities and operators, gun control).

The Pennsylvania chapter of the American Academy of Pediatrics (PA AAP) has developed several projects that illustrate statewide public-private sector collaboration among health professionals. For the past 11 years, the PA AAP has contracted with the state to provide transportation safety education for parents and children. Using funds from the National Highway Transportation Safety Administration, the state government purchases service from the PA AAP to link the public and private sector resources to promote car seats, seat belts, pedestrian safety, bicycle safety, and school bus safety, and to prevent the use of alcohol and other drugs, and dangerous driving behavior by teens. The PA AAP's Early Childhood Education Linkage System (ECELS) is in the fifth year of operation. Now funded by state-administered Child Care and Development and Title V Block Grants, ECELS provides information, training, and linkages with health professionals to improve health and safety in early childhood group care.

ECELS uses immunization and health service data gathered by licensing inspectors from child care centers to identify pockets of inadequate preventive health services. When a licensing inspector finds that a facility's child health records lack documentation of up-to-date preventive health services, ECELS contacts the child care facility to offer linkage with a community health nurse or local pediatrician. The public or private health professional first determines whether the problem involves documentation or an actual gap in service. The health professional then helps underserved families arrange care within the community. ECELS also uses the aggregate data to identify regional and statewide problems of access to preventive health services.

Organizing for Flexible Approaches to the Provision of Care

New sites of service delivery will work only if service providers at the alternative care settings have adequate facilities, achieve a high level of information exchange to coordinate services among providers, avoid fragmentation of care, and receive adequate compensation for service rendered. These arrangements will be temporary experiments unless new modes of service delivery match the needs of families and providers.

Denver's After-Hours Program is an example of an innovation that meets the needs of both patients and providers. Specially trained pediatric nurses use standardized protocols and selected service sites to assure after-hours access to competent telephone advice and to reduce the burden of after-hours pediatric care for physicians. More than 100 physicians subscribe to this service. The cost to the physicians is between 1 percent and 12 percent of their annual net income, including lost revenue from not seeing the patient after-hours. A little more than half the patients are managed by telephone only; 20 percent require an after-hours patient visit; and 28 percent receive advice and are seen the next day in the primary physician's office. In the first four years of operation, 100 percent of the participating physicians and 96–99 percent of patients were satisfied with various aspects of the service.[8]

Other service delivery innovations include arranging for extended office hours by hiring personnel to work those hours when patients want care, or setting up centralized after-hours care sites that coordinate with primary care systems to assure quality care. Some emergency rooms that are overburdened with nonemergency care have set up adjacent walk-in care facilities to which patients are

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sent by a triage nurse. About a year ago, The Children's Hospital of Philadelphia established such a service. This low-intensity walk-in service (called "fast-track") is an adaptation to the behavior of families who seek after-hours care from the emergency room for their mildly ill children. Patients receive written information from the visit to take to their child's usual source of primary care.

Promotion of school-linked health care deserves qualified support. Some health services may be more effectively provided at child care facilities and schools. For example, developmental assessments of young children may be more reliable when performed in natural settings by people who know the child well. The three-dose regimen for hepatitis B immunization of teenagers could be provided in school so children do not have to make three trips to a health care facility. Traditionally, schools have performed sensory screening; however, few child care and school facilities have suitable environments for confidential examinations and technically adequate comprehensive screening. Recently renewed interest in family service centers at sites convenient to the community is reminiscent of the settlement houses of the early part of the century. Some of these new centers, however, may be little more than an effort by the schools to bring in increased revenue. Poor-quality, fragmented, and duplicated services will result unless these sites of service assure that parents are involved appropriately, that the child has care informed by the child's medical history 24 hours a day every day of the year, and that a mechanism exists for exchanging data with the child's other sources of health care.

Any site where families congregate in the community offers an opportunity for health education and health promotion. Outpatient waiting areas can show educational videotapes of good quality and offer interactive computer/video health education games. Waiting lines at food stores, exhibits in shopping malls, traveling educational programs for child care and school curricula, mass media, and educational videotapes stocked at commercial video stores hold great potential for communicating health messages. One national fast food restaurant chain (McDonald's®) has entered into partnership with immunization advocates and will use tray liners and prizes as incentives for complete immunization of children. The exercise courses found in many communities provide ongoing messages about fitness. Better use of ordinary places to remind residents about fitness activities in the course of daily duties could further promote participation. Posting reminders on low shelves of grocery

stores, for example, could remind shoppers to bend and lift with the knees, and teach lessons about healthy back care.

NATURE AND SCOPE OF SUPPORTS NEEDED BY PRIVATE PROVIDERS TO TAKE ON THESE CHALLENGES

Bright Futures: Guidelines for Health Supervision of Infants, Children, and Adolescents presents a broad scope of practice for the typically developing child. As health care reform moves from proposal to program, incentives should be provided to deliver the package of preventive services. The design of the service system must foster relationships that strengthen the therapeutic alliance between health providers and families. Payors must compensate providers fairly for time spent delivering comprehensive care and must use relatively invisible measures to account for services provided. Private practitioners must be more involved in teaching medical students and residents and in conducting research on how to function effectively in a primary practice setting. The time spent by practitioners in these activities should be fairly compensated, not donated.

Human service providers within the same community should not have to discover each other by accident. Orientation for new providers who enter the community should include information about how to coordinate with other services and how to work with local systems to get paid fairly for work. Orientation should be seen as a welcoming service for professionals and supported as a public health activity.

To make the systems work (and not just increase the hassle), private practitioners should participate in designing, implementing, and staffing the systems in which they are involved. New condition-specific protocols are being developed by national professional organizations. If these are tested and validated in practice, they will help improve quality of care and limit medical liability for the professionals who follow them.

Children with special needs require additional services. To avoid more costly dysfunction and wasted services, coordination of care must be a compensable service. Many children have special needs, but the complexity of problems varies from one child to another. Professionals who work with children and families need a mechanism that provides fair pay when service requires extra time. Implementing a pediatric-specific Resource-Based Relative Value Scale may offer appropriate incentives. With enhanced compensation to offer health providers, families with complex problems might become empowered partners rather than dependent supplicants in their interactions with health professionals.

New services should be vigorously marketed to all providers with whom the service might link families. Within a community, joint training of support staff where common content is involved would promote interpersonal relationships across service systems. For example, child development is a topic of common concern for social service, auxiliary staff in health agencies, and child care facilities. Community colleges could offer training on core topics within a given community, and arrange for appropriate credentials for individuals within their own professional system. Knowing someone by name in another agency makes contacts on behalf of clients/patients much more effective. Joint training and orientation to services should encompass services for families with special needs (whether or not these needs include a child who has special health problems).

Access to support systems must be improved at the community level. We must stop proving over and over that home visitation is an effective intervention for young families. We should implement a universal home visitor program for pregnant women and for newborns, with continued service for families who need extra support. Home visitors must be competent in the cultures of families as well as health care systems so they can function as advocates for both. We need routine, effective communication between primary care providers and tertiary care subspecialists. Relationships between primary care and tertiary care providers must be built on mutual trust and respect for the roles each plays in promoting health. To serve patients with complex needs, one case manager should be designated to communicate with families and all service providers (*not* one case manager for each program serving the family). Where multiple case managers are involved, a clear decision should be made about which one can most appropriately serve the needs of the child and family.

Public health authorities must be charged with organizing systematic approaches to deal with stressed single-parent families, parents who abuse alcohol and other drugs, abusive parents, intellectually limited parents, culturally disparate families, families with genetic disorders, and noncompliant families. Private practitioners should be able to contact a pool of resource professionals when such families exhaust or exceed the abilities of the ordinary practice.

Finally, the computer whiz kids in business must strive to make electronic information gathering, recordkeeping, business systems, and health education tools that are safe, user-friendly, time-saving, cost-saving, and capable of improving patient and provider outcomes, including satisfaction. The keyboard must replace the piles of paper that preserve confidentiality only by getting lost repeatedly. The secrets of health records might be better protected by electronic systems than by the current paper process. Charts are routinely left outside examining room doors and on desks, misplaced, or copied by clerks on signed request from an individual claiming to be the child's parent.

CONCLUSION

As a national officer and spokesperson for the American Academy of Pediatrics, I am an advocate for children and for pediatrics. Our response to health care reform should not be just to plan for the future—we must make the future happen. If we feel overwhelmed by the challenge, we must remember the Amish schoolhouse saying: "I am just me, but I am still someone. I cannot do everything, but I can still do something. Just because I cannot do everything does not give me the right to do nothing."

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CHIP—A Community Model for a Comprehensive Health Care System

INTRODUCTION AND OVERVIEW

The Child Health Investment Partnership (CHIP) is a public-private partnership providing a system of health care delivery to medically underserved children in Virginia's Roanoke Valley and in eight communities throughout the state. The partnership's mission is to promote the health of children and strengthen their families by using a mix of public and private resources to ensure a community-based system of primary heath care, care coordination, and family support.

CHIP was established in 1988 to address weaknesses in Roanoke's primary care system for young children. At the time of CHIP's inception (1987), 27 percent of children ages birth to six years (4,800 children) were living in families with incomes below 150 percent of the federal poverty level. Having

by
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a Medicaid card was not an adequate solution for ensuring that children in poverty would receive health care. Only one out of 16 pediatricians accepted new Medicaid patients, and family practice physicians generally limited the number of Medicaid patients per month they accepted into their practices (if they accepted them at all). Low Medicaid reimbursement rates were cited as the primary reason for not accepting these patients.

In the public sector, health departments offered only well-child services on a limited basis, and the absence of 24-hour coverage led to inappropriate use of emergency rooms as a source of primary care. The hospital clinic held four half-day clinics, and, like the health department, lacked 24-hour coverage. Immunization rates in the area for two-year-olds were only 52 percent. Additionally, there was a lack of coordination and outreach between public and private services and programs such as the Special Supplemental Nutrition Program for Women, Infants and Children (WIC), immunization clinics, and mental health and social services. Fragmentation, duplication, and delivery of care in inappropriate settings (or not at all) were the major concerns echoed early in CHIP's development.

Setting the Stage

A group of health leaders with firsthand knowledge of the deficiencies in the system convened a meeting in Roanoke in May 1987. In attendance were private physicians, public health directors, a state senator, local community action agency staff, the Virginia Commissioner of Health, chairs of pediatrics departments in Virginia's three medical schools, and others knowledgeable in the area of health care. The philosophy and ideas that were to become the key elements of CHIP were developed at this meeting.

A task force was formed to further refine the ideas and build them into a working model. CHIP was launched in 1988 as a public-private partnership with initial funding from the Maternal and Child Health Block Grant. The W. K. Kellogg Foundation was so intrigued by the model that it granted CHIP $1.5 million in support for its first three years of existence. CHIP is now incorporated as a 501(c)3 organization. A board of directors with wide community and corporate representation oversees the organization.

After funding CHIP of Roanoke, the W. K. Kellogg Foundation awarded a second grant in order to replicate the program model in other communities in the state, beginning in July 1990. The goal of this expansion project, known as CHIP of Virginia, is to establish a statewide network of community-based projects offering comprehensive health care to children of low-income status and multiple support services to their families. The expansion program has retained the concept of the public-private partnership with three participating partners: community action agencies, health departments, and private physicians and dentists. Because each site has a unique combination of demographics and resources, organizational structures may vary, although program components do not.

The CHIP Model

CHIP models a family-centered system of care at the community level that ensures a broad range of available and accessible services for the target population. Comprehensiveness, coordination, and continuity are emphasized in the CHIP framework. The founders recognized that medical care was only one facet in making a difference in the health status of these children. The definition of health within the CHIP model is linked to the environment, prevention, primary care, and coordination of services such as transportation, housing, nutrition, mental and physical health, and to other social supports.

The CHIP model has three basic components: providing care coordination, facilitating children's access to primary health care services, and providing family support services.

CHIP creates a "medical home" for each child by designating a local private physician to care for the child. Within this medical home, the child has access to regular and continuous medical care 24 hours a day. Public health nurses provide care coordination services, through which CHIP staff establish and implement a comprehensive health care plan for each child in the program. Furthermore, families in the CHIP program receive support services such as parenting, health and nutrition education, and transportation to appropriate services. The public health nurse and home visitor work together to coordinate care and deliver services to the child and family. All children are referred to a locally based single point of entry. Public health nurses and home visitors conduct family-oriented child assessments and make referrals to an integrated network of services.

CHIP targets services to children, ages birth to six years, whose family income is below 133 percent of the poverty level at the time of enrollment, and below 150 percent at recertification each year thereafter. Each year since CHIP's inception, the upper age limit has been extended by one year so that an enrolled child does not lose eligibility because of age. CHIP serves the cities of Roanoke and Salem and three surrounding counties. The area comprises 1,100 square miles and represents urban, rural, and suburban populations; 67 percent of the children being served reside in the city of Roanoke.

LOCAL SYSTEMS DEVELOPMENT

Facilitating Local Planning and Action

CHIP fosters the process through which system development can occur. Drawing on the Roanoke experience, increasing or enhancing the community's capacity to promote access to health care within the CHIP framework has occurred in several stages. These have been translated into the following strategies in the replication effort: (1) building interorganizational partnerships within local communities including the private medical sector; (2) developing and maintaining responsiveness to local needs; and (3) cultivating resource development by finding or creatively combining channels of funding.

Strategy #1: Building partnerships.

The public-private partnership approach is the cornerstone of CHIP. The Roanoke model reflects a true grassroots approach, while the CHIP of Virginia sites are really hybrids in which the basic project framework is provided to localities in general terms, allowing for considerable flexibility and variability at the local level.

Based on the Roanoke experience, development of CHIP partnerships requires that participants meet certain conditions: collaboration, leadership, and clear vision. First, the partners must be willing to collaborate (i.e., share resources, create a shared vision, and share in the solutions and the successes).

Development of local CHIP partnerships initially includes three key participants—the local health department, the community action agency, and the private medical community. A principal strategy for revising frontline service delivery focuses on convening leaders who represent these three key participants.

The second condition is leadership. Building the partnership means selecting participants with the power and authority to effect change and open doors in the community. CHIP of Virginia, in replicating the initial Roanoke model, uses basic principles of community action, capitalizing on the local and state networks of providers and professional organization leaders in nursing, medicine, public health, and community action in order to identify and cultivate leadership within communities. Typically, local advisory boards include health directors and directors of public health nursing, executive directors of community action agencies, and leaders within the local pediatric and family practice community. Thus, the CHIP process bridges the gaps that exist with respect to the visions of established health providers (including public health providers), other community agencies, and consumers. In developing and implementing the partnership, it is important to include agency staff at several levels throughout the partner agencies—by integrating support and participation at different levels, the partnership has a much better chance of survival, should the top leadership suddenly change.

The second condition is leadership. Building the partnership means selecting participants with the power and authority to effect change and open doors in the community.

The third condition involves clarity of vision. To guide development, attention must be given to articulating a clear mission and clearly identifying the population to be served. CHIP's target population comprises children ages birth to six years from families below a defined income level, regardless of their insurance status. Serving this population also includes working together to integrate health and social services, paying particular attention to the social contributors to ill health. Completing a community needs assessment that contains basic demographic information as well as an assessment of

community services and resources forms an important basis for tailoring CHIP to the needs of a particular community. Families are encouraged to express their views, thus providing further insight into the needs of the community.

Strategy #2: Maintaining responsiveness to the community.

The second strategy is to maintain responsiveness to local community needs. Thus far, the CHIP experience finds the following factors to be of great importance in maintaining responsiveness: (1) commitment of leaders; (2) local autonomy and control; (3) the ability to communicate effectively to solve problems; and (4) the capacity for supportive data linkage systems.

CHIP works to ensure community responsiveness and develop the capacity to meet the needs of the population by reaching out simultaneously to those within as well as those outside mainstream health, education, and social services and to include religious, business, and civic communities. This requires committed leaders who are willing to devote their time and energy to bring together a seemingly disparate group. It also requires leaders who remain committed for an extended period of time. Those involved with CHIP of Roanoke in 1988 are still active today.

Development of partnerships inherently involves altering deeply entrenched patterns of interactions between traditional service providers.

Development of partnerships inherently involves altering deeply entrenched patterns of interactions between traditional service providers. Turf issues have existed and undoubtedly will surface again as CHIP continues to evolve. Addressing turf issues is vitally important to ensuring success. Taking risks, trusting other agencies, and remaining focused on a shared vision has enabled CHIP to succeed. The technical assistance and guidance provided to the developing CHIP sites focuses on enabling institutions that serve the same families to solve common problems. As the cross-site evaluation of CHIP moves forward, we must wait for the results of the impact of local factors on program development.

Community-based policies need to be locally driven. Autonomy and control at the local level foster the sharing of accumulated learning that the partners bring to CHIP. This allows the emerging system to be more responsive to contextual changes and implementation issues within the community and to resolve problems and concerns more quickly than within the confines of an established bureaucratic entity.

Remaining responsive to a community's needs also requires developing the capacity for supportive data systems and information system linkages. The impact of the project must be demonstrated to funders, to the community, and to staff. Linking data systems with providers and agencies is difficult to achieve but is essential to demonstrating the results in terms of outcomes. Concern about confidentiality is an important issue that still needs to be resolved at CHIP. Currently, CHIP's data system is linked with the health department, and providers under contract send copies to CHIP of all encounters with children served by the project. Linkage of data systems with agencies such as social services remains a long-range goal.

Strategy #3: Financing the effort.

The third strategy for increasing system capacity—and one of the most critical—is funding. Ultimately, the availability of funding determines whether the revised services delivery structure will become widely implemented and permanently established and also determines the size of the population that can be served effectively. Like many other innovative ventures, CHIP has had to find piecemeal funding in order to transform a piecemeal health care system for children and families into a coherent one. The most important lesson gleaned from project experience is not to be bound by a task orientation to funding sources. Thus far, in the absence of a stable funding base, a creative mix of public and private funding sources has meant survival for CHIP.

The Roanoke project is a good example of the collaborative approach and its importance to resource development at the local level. In Roanoke, the first step was to ensure that services were not being duplicated. Broad-based community support and representation on the board of directors of the

Roanoke project has been essential in developing a system that has maximized the use of existing resources. Involving the corporate sector yields benefits that include an increased awareness of child health issues, financial support (including in-kind support), and an entry into segments of the community that may be unknown to those in the medical profession. Corporate leadership on the project's board of directors has helped promote fiscal accountability and has led to the creation of a business plan to guide development activities. One notable example of this type of support for CHIP is the establishment of a permanent fundraiser supported by Blue Cross/Blue Shield. Evaluating the role of private sector fundraising is being monitored closely by all involved in this effort.

Funding for CHIP of Roanoke is a mix of public and private money. Currently, public funding constitutes 50 percent of the project's $800,000 budget, from sources including the Maternal and Child Health Block Grant, local governments, and Medicaid revenue for expanded services such as case management and transportation. Local government funding, which plays an important role in the project, is assured through the commitment and leadership of the CHIP partners. Private sources of funding—corporate and individual donations and private foundations—comprise the other 50 percent of the Roanoke project's budget.

Medicaid, the main source of funding for the primary health care of children enrolled in CHIP, plays a significant role in the project. Currently, 85 percent of children in Roanoke are enrolled in Medicaid and that figure approaches 100 percent in the replicate sites. CHIP has not yet found Medicaid to be a substantial source of revenue for the case management services provided by the public health nurses.

Statewide, new funding streams are continually being sought; recently, CHIP of Virginia (the replication effort) was awarded a Family Resource grant of $4.5 million from the Administration on Children and Families, U.S. Department of Health and Human Services, to support and expand project services across the state. The challenge is to find permanent funding channels and predictable levels of support on a continuing basis to enable long-term planning for service delivery. CHIP is working with key leaders and the business and medical community in the state to advance a legislative mandate to sustain the project.

Private Medical Sector Participation

Thirty-two pediatricians and family practice physicians from nine private practices provide the primary health care for children enrolled in the project. The strength of the CHIP model is that the enrolled child has the benefit of a primary care provider on a continuous basis. Private medical sector participation can be credited largely to the involvement of the medical community in planning and implementation of the project at the local level. Physician participation on local advisory boards develops the practitioner's awareness of community need, provides a forum for exchanging information with others involved in delivering health care (such as public health providers), and establishes a means of expressing concerns and solving problems concerning the provision of primary care.

A 1991 Virginia Polytechnic Institute study of medical sector participation of CHIP providers found that physicians were "hard pressed" to find weaknesses with the program; most physicians, in fact, did not report any weaknesses, but enumerated a number of strengths, including completed health histories, up-to-date immunizations, good continuity of care, a medical home, improved appointment compliance, and family involvement. Practitioners typically report that it is difficult to uncover factors that may affect health outcomes in office-based practices that are becoming increasingly burdened with the advent of managed care in the Roanoke Valley.

A powerful incentive for CHIP involvement cited by the majority of participating physicians is the range of comprehensive services provided by the project, largely through care coordination activities by public health nurses. These care coordination activities augment the services provided by physicians in private practice. The public health nurses coordinate treatment plans when appropriate and help manage the social/economic barriers that may impede resolution of health care problems. The nurses assess the child within the context of the family and focus on prevention—tracking and reminding parents when the next immunization, dental, or well-child check-up is due, making referrals to resources such as WIC, or facilitating parent classes. Home visitors conduct family needs assessments and follow up on missed appointments. These services help to improve family compliance as well as reliance on the physician as the child's medical home, and result in increased satisfaction for both the family and the CHIP provider.

STATEWIDE INITIATIVES

CHIP staff remain informed of and involved in statewide changes and initiatives that affect the health of children and families. Many of the needs across the state affect the development of new CHIP sites. In Virginia today, there are 1 million uninsured citizens. Sixty percent of all counties fall below the nationally recognized standard to ensure adequate primary health care (i.e., one primary care physician per 2,500 people). More than one-third of all Virginia counties are officially designated as medically underserved communities or health personnel shortage areas.

Several initiatives have been enacted to meet the challenge of ensuring adequate capacity for primary health care. Four years ago, the state passed a resolution (SJR 179) authorizing local health departments to assess the primary care needs of populations within their jurisdictions; these assessments identified weaknesses in the primary care system throughout the state.

During the same period, then-Governor L. Douglas Wilder created a task force to address the primary heath care needs of children. A final report, published in 1991, contained recommendations for a package of primary and preventive care for children. In addition, other initiatives included (1) forming the Virginia Health Care Foundation (1992) to promote cooperative primary health care initiatives involving public-private partnerships across the state; (2) supporting the 1994 Virginia Generalists Initiative to ensure that 50 percent of Virginia's medical school graduates enter general practice by the year 2000; and (3) establishing the Virginia Area Health Education Centers in 1991.

The CHIP Statewide Coordinating Council was formed in 1990, when the $2.3 million replication grant was awarded by the W. K. Kellogg Foundation. Council representation reflects the local communities, with representation from medical education, professional organizations, community action, public health, Medicaid, and private insurers. The council advises on project implementation statewide, and exerts considerable influence in helping to permanently establish the model statewide.

CROSS-PROJECT EVALUATION

Evaluation of the Roanoke model program and the first three CHIP of Virginia replication sites (Abingdon, Charlottesville, and Richmond) is under way. The principal investigator is Lorraine Klerman, Dr.P.H., M.P.H., of the University of Alabama at Birmingham School of Public Health. Mary Rogers, Dr.P.H., M.P.H., also of the University of Alabama at Birmingham, serves as project director for the evaluation.

The evaluation plan encompasses three phases.

Phase I: Developing a data collection system for CHIP Roanoke and the replication sites.
This data system would describe:

- The number of children and families enrolled;
- The number and type of medical and dental encounters;
- The number and type of public health nurse encounters and family intervention specialist encounters;
- The sociodemographic and health characteristics of families; and
- The cost of the projects (Roanoke model and replication sites).

Phase II: Designing and implementing a process evaluation of the replication sites.
The overall goal of the process evaluation is to determine whether CHIP programs in the replication sites are operating in ways that will make it possible to meet primary objectives of the project: "To build and maintain a network of local/private partnerships to improve the health status of young children to enhance each participating family's ability to move towards self-sufficiency." The process evaluation is designed as a formative evaluation and the information obtained will provide feedback to help monitor current implementation and expansion to additional sites.

Phase III: Developing a design for a prospective evaluation of at least five CHIP sites (four replication sites and the Roanoke model).
Planning and design for the prospective evaluation of CHIP began in January 1994. This phase will use the data collection systems and lessons learned from the previous phases of the evaluation. The

prospective evaluation will be a long-term study in which at least two years of data will be collected and analyzed.

Medical and dental utilization and diagnosis data will be collected from Medicaid data tapes. These tapes contain the information used by the Virginia Department of Medical Assistance Services to track health care services to Medicaid recipients and to bill providers at standard Medicaid reimbursement rates. The tapes also capture hospitalizations and emergency room utilization for Medicaid-enrolled children. For strict confidentiality, all names and other personal identifiers will be removed before data are sent to the University of Alabama at Birmingham.

Medical and dental coverage for children in low-income families is changing with the advent of Virginia's Kids Care program and with Blue Cross/Blue Shield's Caring program. CHIP replication sites and the Roanoke model are actively seeking partnerships with these programs so that children who are not eligible for Medicaid can be enrolled in local CHIP programs with assurance of reimbursement for CHIP medical and dental providers. Blue Cross/Blue Shield may also provide access to medical and dental utilization data through their management information systems.

CONCLUSION

CHIP continues to evolve and to exert positive influence on local and state systems of health care for young children. In the shadow of health care reform, CHIP is searching for ways to fit into the "big picture." It is important to keep in mind that whatever emerges from the health care deliberations of federal policymakers, implementation will occur at the local level. Meaningful involvement of all stakeholders in needs assessments, planning, and implementation has made CHIP successful, and the experience demonstrates that meaningful change can occur with committed leadership from communities.

Pediatric Primary Care Systems Development Initiatives in Arizona

The responsibility for assuring that all of Arizona's children have access to and utilize primary care services was introduced in the late 1980s with the special set-aside funding through the Maternal and Child Health Block Grant, and was formalized with the passage and implementation of the Omnibus Budget Reconciliation Act of 1989 (OBRA '89). The purpose of this paper is to describe how the Arizona Department of Health Services has attempted to address this challenge. It includes a description of the state of Arizona within the context of service delivery, a bit of history in relation to primary care, a description of the planning process used, and the resulting strategies and programs.

Arizona is typical of many western states. Geographically, it is a large state with broad expanses of uninhabited land. Arizona, however, is an urban state, with almost 80 percent of its pop-

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ulation residing in three urban areas. The state's population is fairly ethnically diverse: 27 percent of Arizona's children are Hispanic, 4 percent are African American, and 8 percent are Native American. A total of 22 Indian tribes live on reservations in Arizona. Most Native Americans are served by the Indian Health Service or by a tribal health department. Fifteen autonomous county health departments provide many typical services such as sanitation, disease control, immunizations, and community nursing. These county health departments, for the most part, are not primary care providers.

Arizona's Medicaid system consists entirely of managed care. Almost all of the system is privatized, and county health departments are not Medicaid providers. The Medicaid system is administered by a state agency specifically created for that purpose. All persons enrolled in the state's Medicaid system select or are assigned a health plan and a primary care provider. The number of plans varies from year to year depending on the number of proposals submitted and the actual "bid."

THE CHALLENGE FOR ARIZONA'S MCH PROGRAM: WHERE TO BEGIN?

The challenge faced by Arizona's MCH program was similar to the challenge facing many states: "Where in the world do we begin?" The first task was to determine what was happening—some would call it a needs assessment. The Department of Health Services MCH program used the set-aside funding from the federal Maternal and Child Health Bureau to conduct a survey to determine utilization of primary health care. It was discovered that all of Arizona's children were faring poorly; there were no significant differences based on income levels or insurance coverage. In fact, the greatest predictor of utilization was whether the family had a usual source of care.

With this information and a knowledge of the state's service delivery systems, the next step was to develop a plan. This is where the serious struggle began. Several things worked in our favor. We had

examples of "systems" that integrated private and public sectors, various payors, and various delivery models to address the needs of specific populations successfully. The private and public sectors work well together. Within the Department of Health Services, Office of Maternal and Child Health, there was general agreement that the focus for assuring primary care for children would be at the community level, and we were reasonably certain that what might work for one community might not be a successful strategy in another. On the other hand, it was unclear what "primary care" should include, or what the "system" should look like. It was sort of like making a chocolate chip cookie without ever having baked one before and without having a recipe. We not only didn't know the recipe, we couldn't find anyone else who did. We vacillated between trying to figure out what to do and doing "something"—and finally decided to try "something."

One of the major interventions emerging from community planning is the school-based or school-linked clinic.

The first attempt involved contracting with three community agencies to develop and implement a plan for primary care for their community. The idea was to use a community development process to develop the plan. It was a learning experience. We didn't know what we really wanted these community agencies to do—except to assure that all children had a medical home. So the agencies were not given much direction. Since each of the contractors was a community agency, it was assumed that each knew how to "do" community development. This was not the case. Then it was discovered that staff within the state Office of Maternal and Child Health did not have the skills needed to provide technical assistance. It was a frustrating experience for all.

In 1992, the Department of Health Services decided to begin again. Many people at the national level had been working on the issue of primary care, so more resources were available. In addition, the Maternal and Child Health Bureau had published a definition of primary care, and Dr. Barbara Starfield had developed a model that defined the attributes of primary care and identified the structure and process characteristics of a primary care system.

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TASK FORCE OBJECTIVES AND OUTCOMES

With those resources as a guide, a statewide task force was created to mobilize state agencies and community representatives to develop a comprehensive plan that would ensure coordination of primary care services. The task force, by design, represented the broadest membership including the health community, education community, business community, health care financiers, consumers, rural communities, and urban communities. The task force focused on developing the concept for a statewide system, planning objectives and strategies for action, and building consensus among public and private sectors.

The goal was to provide the Arizona Department of Health Services with recommendations for designing a system to ensure that all children have access to and utilize primary health care. This system must be family centered and community based, and must meet primary care needs as well as special health needs for children and their families.

The task force identified three objectives:

1. Develop and promote a common definition of primary care;
2. Formulate statewide policies that support universal accessibility and utilization of services; and
3. Activate strategies that assure implementation of statewide policies, including the need to measure how well the system or systems are currently meeting the definition of primary care.

The task force defined primary care as follows:

> *Primary care for children and adolescents is a personal health care service that is delivered in the context of family and community. It is comprehensive in scope and includes services that preserve health, prevent disease and dysfunction, and care for common illnesses and disabilities. Primary care is the usual point of entry to the personal health care system.*

Task force outcomes include a blueprint, marketing plan, community development efforts, various options for service delivery, and increased training and technical assistance. A brief description of these efforts follows.

The task force was instrumental in defining the model of primary care in the state. It was a challenge to understand how the attributes were to be applied and how one model could respond to the needs of every community. After considerable debate within the task force and Office of Maternal and Child Health staff, the idea of a blueprint was developed. The task force used the example of an architectural model, in which a standard blueprint would be developed for a three-bedroom, two-bathroom house; many people might have the same blueprint but their houses would all look different depending on the tastes and needs of the individual families. This blueprint concept also would hold true for a primary care system at the community level. The job of the task force was to develop the blueprint that a community would use as the basis for its own system. This seemed like a relatively simple concept, but it was a major accomplishment for both the task force and MCH staff. It helped everyone understand how to develop a primary care system.

The second outcome of the task force was the creation of a committee to develop and implement a marketing plan. No one on the task force knew much about marketing, so members contacted the college of business at one of the universities and arranged for a graduate student in marketing to work as an intern to help the subcommittee develop the marketing plan. The plan was to be pilot tested in two "typical" Arizona communities in 1994. The committee continues to be very involved in this activity, and the intern extremely valuable in providing the staffing and technical assistance to the committee. Apparently, the internship also is an excellent experience for the students because each semester brings increasing competition for the assignment; the current intern assumes responsibility for recruiting the successor.

The third outcome of the task force involves an increase in community development efforts. The Department of Health Services is committed to the concept that communities are the best resource for effecting system change, and thus initiated local planning grants. Planning grants of $5,000 each

have been awarded to 15 local agencies to develop primary care systems for their communities. Local grantees must use a community development model to develop the plan, which must include an assessment based on the primary care attributes, an intervention plan, and a financing plan. Most of the contractors are schools, school districts, or county health departments. Some of the contractors are in the intervention stage and all have acquired financing from the community.

The task force's fourth outcome was identification of a variety of service delivery options. To date, there are at least five options, and presumably there will be more. One of the major interventions emerging from community planning is the school-based or school-linked clinic. A few years ago, this option would not have been considered; now these clinics are being financed through a variety of mechanisms such as fee for service, grants, and foundation support.

A number of programs may be effective in themselves, but do they change the system for the state's population of children? This is clearly the next challenge.

Another service delivery option is the Medical Home Program, a collaborative effort between the Arizona Chapter of the American Academy of Pediatrics and the Department of Health Services. The basic concept of the program is to match pediatricians and family practice physicians with a school in their neighborhood. The physician agrees to provide primary care for a certain number of children. The school nurse identifies children without a primary care provider and without insurance and matches a child with a volunteer provider. The program is being pilot tested in an urban community but other school districts and providers have shown a great deal of interest in the program.

A third option is the Passport Project, targeting the newborn population. This concept involves a parent-held medical record with a tracking system included. The Office of Women's and Children's Health has been working with Dr. William Frankenberg in the development of the "passport."

Community-based outreach programs and nurse practitioner clinics complete the primary care service delivery options currently operating in Arizona. The community-based outreach uses lay work-

ers to assist families in gaining access to primary care in their neighborhood or community. The nurse practitioner clinic is a free-standing clinic in an underserved area, with oversight provided by a university college of nursing. Each of these may grow in appeal with the advent of health care reform.

All of these task force activities have generated an increasing need for consultation, training, and technical assistance within communities. Therefore, the Office of Women's and Children's Health has developed the capacity to provide consultation and technical assistance, including training, in the following areas: community development, school-based clinics, contracting processes, sustaining of funding and marketing, and the medical home program. We have trained a number of our staff to provide consultation on community development, using existing materials from the Centers for Disease Control and Prevention and other sources.

Consultation and technical assistance have been critical for the development of school-based clinics. Technical assistance includes a range of information about issues such as licensing requirements, staffing requirements, and financing mechanisms. Technical assistance is provided to individual schools or agencies. Monthly meetings are held so individuals involved with the development of clinics can share information and successes. The medical home training project, a joint effort of the Office of Women's and Children's Health and the Arizona Chapter of the American Academy of Pediatrics, is provided to interested primary care providers regionally throughout the state.

CONCLUSION

It is apparent that a great deal of activity surrounds the issue of primary care for children in Arizona. In fact, there is so much excitement in the state that it is hard to keep up with it. One of the most exciting results is the change in the "culture" of the Office of Women's and Children's Health. Although this paper presents only a partial listing of primary care activities and programs in the state, the Office of Women's and Children's Health has integrated within virtually all of its programs the concern that all of Arizona's women and children have access to and utilize primary care.

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With all of these efforts, a clear need for evaluation exists. Evaluation needs to occur on at least two levels. The first focuses on the individual strategy level. Therefore, each of the projects or programs listed above has (or will have) an evaluation component. Second, there must be evaluation on the system level. Returning to my earlier metaphor, the question is "Do we have a chocolate chip cookie?" A number of programs may be effective in themselves, but do they change the system for the state's population of children? This is clearly the next challenge. Any advice, direction—and help—are welcomed!

Health Care Reform and Public Health Considerations in Alabama

INTRODUCTION

This paper describes the Alabama Department of Public Health (ADPH) and its activities providing personal health care in this time of health care reform. This paper focuses specifically on (1) strategies that ADPH will consider to maximize the opportunities in health care reform to fashion a system supportive of maternal and child health services, and (2) responsibilities for assessing the effectiveness of the postreform system. Certain aspects of this discussion at the time of the April 1994 workshop have evolved in meaning, as the assumption of universal coverage through national health care reform legislation was not realized during the 103rd Congress. Without universal coverage, it simply may not be feasible for public health agencies providing personal health services to

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cease doing so. With erosion of public programs, monitoring the effectiveness of the reformed health care system becomes even more vital. The substantive portion of this discussion considers public health in relation to the developments of managed care in the private sector, and that discussion remains at the core of reforms—both before and after the 103rd Congress.

The Alabama Department of Public Health is not part of the Governor's cabinet; it is an independent state agency, governed by the 16-member State Committee of Public Health. Twelve of the members are elected by the Medical Association of the State of Alabama, and four are selected by health-related committees. The Alabama Department of Public Health is typical of health departments in some other states (particularly in the South) that provide a substantial portion of personal health services. Provision of personal health services by ADPH, however, poses an institutional dilemma. The significant increase in provision of personal health services by ADPH during the past decade results from the increased need for those services within the population, increased sensitivity to previously unmet needs for such services, and available reimbursement. Consequently, the department expanded significantly, developing the facilities, staff, and expertise to deliver the needed services.

The department's current structure depends to a great extent upon the revenue realized from the provision of personal health services, and this revenue is used to subsidize core public health functions. Thus, Alabama's health care system is heavily dependent upon the nature and extent of the services provided by ADPH. While the department and other providers serving low-income and uninsured populations have developed specialized capacities and skills to serve the special needs of these populations, private sector providers have not. Examples of this specialized care developed in the public sector (and not normally found in the private sector) include extensive use of social work and care coordination assistance for patients, near "monopolization" of provision of care for tuberculosis, and dominance in care for sexually transmitted diseases and HIV-affected pregnancies.

Alabama may be somewhat unique among the states in that its health care reform task force is housed in the public health agency. In most states, a task force or commission has been appointed by the legislature or governor. For reasons described in more detail below, the Governor of Alabama asked the State Committee of Public Health to make recommendations concerning how the state

should respond to federal initiatives on health care reform proposed in 1994. The State Committee of Public Health selected a diverse 80-member task force operating through six subcommittees to study the issues and make recommendations. The diversity and credibility of the task force members and the relatively independent and nonpartisan nature of ADPH offers some hope that the Health Care Reform Task Force recommendations, when presented, will be seriously considered by the Governor and legislature.

This paper addresses two principal themes: (1) how to transform the state's current two-tiered system of health care into a system that provides significantly stronger primary care services and necessary access, and (2) how to transform the activities of ADPH to complement and support the reformed health care system. Thus, we need to imagine not only the reformed health care system we desire but also the role that ADPH would play in that reformed system. Equally important are the transition questions. There is a real downside risk that, with financial access assured and/or significantly increased reliance on managed care delivery arrangements, some public sector providers would cease to provide services. This would result in a health care system with diminished capacity just as demand and financial access increase. There is significant philosophical sentiment that the government should not provide health care services to those with the financial ability to obtain services in the private sector.

DEPARTMENT OF PUBLIC HEALTH AS PROVIDER OF PERSONAL HEALTH SERVICES

For years, most health departments have provided some personal health services; however, the services provided by ADPH have increased tremendously during recent years. The following demographic data provide context for the discussion. Alabama has a population of about 4.1 million persons, with about 62,000 births annually, and an overall infant mortality rate of 10.5 deaths per 1,000 live births. Approximately 25 percent of the state's population is African American, and significant racial inequality persists. The infant mortality rate is 15.8 for African American infants and 7.5

for white infants—a relative risk of 2 to 1. This racial disparity is prevalent throughout all socio-economic indicators. African American residents of Alabama are 75 percent more likely to be without health insurance than white Alabamians. Because of relatively high rates of uninsured populations and relatively low levels of personal income, and because of significant disparity in health care resources between a sophisticated medical community such as Birmingham and the minimal medical resources in some of the poorest rural counties, Alabamians spend the sixth highest percentage of income on health care of any state in the country.

The Alabama Department of Public Health operates 89 clinics, with at least one clinic in each of the state's 67 counties. These clinics offer a variety of personal health services for specified conditions or populations, but, with few exceptions, do not offer comprehensive primary care.

During fiscal year 1993, the magnitude of these specialized and largely uncoordinated services has been substantial.

- Maternity care: ADPH served nearly 27,000 maternity patients, averaging 5.9 maternity visits per patient, for a total of 159,000 maternity visits during the year. With approximately 62,000 births annually, ADPH is serving a little less than half of all maternity patients in the state. Under contract with the state Medicaid agency, ADPH was the managed care provider in one-third of the counties, and was responsible (either directly or through subcontractors) for all maternity care for approximately 13,000 births.
- Child health: ADPH served slightly more than 36,000 infants ages birth to one year, and an additional 86,000 children older than one year. The department provided newborn screening for approximately 60,000 babies.
- Family planning and women's health: ADPH served more than 96,000 women for family planning services and screened 82,000 women for breast and cervical cancer.
- WIC services: The Special Supplemental Nutrition Program for Women, Infants and Children (WIC) provided nutritional assistance to 226,000 Alabama participants

during the year. On a monthly basis, the program served 26,000 pregnant, breast-feeding, or postpartum women, 36,000 infants, and 57,000 children.

- Home health care: ADPH operates one of the largest home health programs in the country, and provided 1.4 million visits to 17,000 clients during the previous year.

These data illustrate the services provided to women and children through ADPH and the importance of the revenue generated through these reimbursable services. The department's reliance on revenue from federally reimbursable services and on federal grants has increased significantly during the past six years. Health care reform thus poses significant issues for ADPH. Under a health care reform system that would provide health insurance for all citizens, ADPH might cease to provide personal health services and might suffer the subsequent loss of that revenue. Radically rearranged federal financing could significantly change the federal funding channeled to state health departments.

As shown in table 1, reimbursable programs accounted for 44.1 percent of revenue during FY 1993, and all other federal programs accounted for 38.9 percent of revenue. However, the six-year period

Table 1

Sources of Revenue FY 1988–93: Alabama Department of Public Health

	Fiscal Year 1988		*Fiscal Year 1993*		
	$ Million	*%*	*$ Million*	*%*	*% Increase*
Reimbursed	24.2	20.7	121.3	44.1	401
Federal	56.7	48.7	107.2	38.9	89
State	31.4	27.0	39.4	14.3	25
Local	4.2	3.6	7.4	2.7	76
TOTAL	116.5		275.4		136

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shown in table 1 is somewhat misleading with respect to the growth in the state's contribution. During the first year (FY 1988–89), state funding increased by 21 percent; during the last five years (FY 1989–93), state funding increased by only 4 percent. Employment in ADPH increased by 63 percent during FY 1989–93, totaling nearly 6,500 employees. (ADPH is the second largest state agency, second only to the state highway department.) Given the relative magnitude of the source of funds, it is fair to ask whether the Alabama Department of Public Health is a state agency or a state-level federal administrative unit.

Although the shape of health care reform is far from clear, the above description should help clarify the difficult issues faced by public health in a reformed health care system. ADPH is a significant provider of personal health services for women and children, and, to a lesser extent, for the entire population. Currently, the department does not provide a comprehensive and coordinated range of services, nor is it likely to provide these services in a reformed health care system. However, ADPH does have special experience providing services to the most vulnerable populations. As stated earlier, ADPH is financially dependent upon the reimbursable services it provides to patients, in order to subsidize other core functions of public health.

To fulfill the core functions of public health—assessment, policy development, and assurance—in a reformed health care system, ADPH will have to secure the funding and expertise to meet the demands of that new system, while adapting many of its personal health service activities in ways that will continue to serve the population. The transition would be a true metamorphosis and would pose significant challenges, but, as part of a full reform of the health care system, it holds the promise of producing a butterfly.

CONCEPTUAL MODEL OF PRIMARY CARE

The principal purpose of this paper is not to develop a conceptual model of primary care for women and children. Nevertheless, examining a conceptual model with its principal components can foster an understanding of the goals we hope to achieve in a reformed health care system as well as the

transition issues that will arise as the health care system changes. A conceptual model provides a blueprint to which we can move existing components of the current health care system or construct new components for a reformed system.

Alabama is in the first year of a three-year State Systems Development Initiative for children, developed jointly by ADPH and the Children's Rehabilitation Service of the Department of Education. That process embraces primary care defined within a framework of 10 attributes: first-contact, continuous, coordinated, comprehensive, community oriented, family centered, accessible, culturally competent, developmentally appropriate, and accountable. Assessing some of these attributes will help determine the opportunities, roles, and strategies that states might experience with health care reforms.

- Coordinated care: ADPH employs approximately 150 medical social workers throughout the state to help patients access other medical care or social welfare services. Unless integrated service networks or managed care programs develop rapidly in all parts of the state (and there are serious reasons to doubt that they will), coordinated care will not exist. Even if integrated service networks or managed care programs are developed, they likely will provide coordination of medical care only, whereas most of the population served by ADPH clearly needs care beyond that defined in narrow biomedical terms.
- Comprehensive care: As stated earlier, ADPH does not provide a comprehensive range of services, nor is it likely to provide those services in a reformed health care system. Both the mission of ADPH and the political realities would view any significant expansion of care as unwarranted competition with private sector efforts.
- Community-oriented care: Currently, no entity in the state provides true community-oriented primary care. It is doubtful that any entity other than ADPH could provide this facet of primary care to a significant extent. With a few local exceptions, ADPH would have to provide the resources and leadership if community-oriented care is to become part of a reformed health care system. Community-oriented care is particu-

larly important for children because they are most affected by certain community health hazards and least able to make their needs known and to have their needs met.

- Accessible care: ADPH clinics have a mixed score in providing care that is accessible to patients. Generally, these clinics are more geographically accessible but significantly less accommodating to client needs than other systems. Specifically, hours of operation, appointment systems, telephone services, attractiveness of facilities, provider attitudes, and patient perceptions of quality are all areas that could be improved through the opportunities of a reformed health care system.
- Accountable care: More accountable primary care may be the greatest single opportunity offered by a reformed health care system providing universal financial access. Yet, public health agencies may be no better positioned to champion this attribute than any other provider or institution, given the low level of trust in government generally. With the economic freedom to choose a provider, however, the marketplace may increase accountability to a level not previously known in our health care system. Other mechanisms involving the collection, analysis, and publication of provider and performance data are definitely needed; multiple avenues and levels of accountability, supported by significantly improved data, should be encouraged. These avenues of accountability include, at a minimum, public and democratic processes, market mechanisms at both consumer and management levels, and professional accountability.

Mainstreaming the current Medicaid and uninsured populations should open avenues of accountability through the marketplace that currently do not exist for those patients. Yet, the imperfections of the health care marketplace are well known. Steps to ameliorate the imperfections of the marketplace and to create other avenues of accountability are some of the most important tasks in reforming the health care system.

TRANSITION ISSUES: AN OVERVIEW

Health care reform with universal coverage and/or increasing use of managed care presents the dual problem of building a health care delivery system with quantitatively and qualitatively better primary care, and, at the same time, building new capacity for public health to perform new or expanded roles in policy development and assessment. On one hand, public health departments may be decreasing their capacity to provide personal health care as Medicaid patients are moved into private sector managed care organizations; on the other hand, they presumably will be expected to expand their capacity to conduct assessment and policy development. This is a difficult balancing act. Without revenue from patient care services, increased funding for core public health services probably will be essential. Receiving increased funding from financially strapped state governments while decreasing the most visible and politically prominent services is like sailing upwind—it can be done, but careful tacking is required.

Steps to ameliorate the imperfections of the marketplace and to create other avenues of accountability are some of the most important tasks in reforming the health care system.

Transition issues fall into two categories: decreasing the delivery of personal health services, and developing the capacity for assessment and policy development in the reformed system. Both present significant opportunities for improving health and the health care system. This paper focuses primarily on the *strategic* issues of the transition. Discrete issues about personnel, management structure, physical infrastructure, process, and systems design are crucial to a successful transition but are beyond the scope of this paper (and probably beyond this writer).

Transition Issues: Primary Care Services

First, in order to make the transition to a health care system with a strengthened primary care system, it will be essential to assure that the public health resources already developed are not lost to the

health care system. Presumably, there will be pressures to abandon some public clinics and public hospitals or to privatize the system and let the private providers supply the capi to upgrade or maintain the public system. Although certain parts of our system have excessive capacity, that is not true of primary care generally. Decisions to close a program or facility must, of course, be made with caution and attention to the individual circumstances. Beyond the minimal position of "do no harm," health care reform provides the opportunity to convert these public resources creatively into a strengthened primary care system especially well located and experienced in serving the needs of low-income communities.

Issues concerning the transition of these public facilities include (at a minimum) the following:

1. Comprehensiveness of services: To play any significant long-term role in providing health care, ADPH clinic sites must offer comprehensive service. Expansion of services is unlikely for both political and financial reasons; however, because of the client base, some integrated service networks might find ADPH clinic sites attractive in the short term (if utilization could be controlled).
2. Quality of services: Although the quality of services provided by ADPH is presumed to be good, few measures of quality exist. ADPH monitors for compliance with federal standards in programs such as family planning; other services are monitored for compliance using standards developed by ADPH. However, no outcome measures or patient satisfaction surveys are conducted. It is not clear what protocols and standards would need to change if ADPH clinics become part of an integrated service network.
3. Physical facilities: Many ADPH facilities are in poor physical condition and convey an unattractive institutional appearance. For several years, ADPH has sought (unsuccessfully) a $60 million state bond issue to improve local health department facilities.
4. Financial management: Financial management for collection from Medicaid has improved significantly during recent years. However, experience in billing and col-

lecting from other payors is limited, and there is very limited experience with capitated reimbursement.

5. Management structure: The structure is designed to manage 89 clinics, most of which are small and geographically dispersed. This differs significantly from most primary care provider facilities, which are often much larger at individual sites and relatively compact geographically. Salaries in the public sector, in many instances, are not competitive with the private sector, and management ability varies considerably across the state.
6. Public image: As provider of last resort, ADPH has a public image that, while benevolent, carries a perception of lesser quality, accommodation, and individual attention. However, some of the current clients have a positive perception and an appreciation of the care received from ADPH over many years.

Transition Issues: Assessment and Policy Development

The reformed public health system presumably will be responsible for providing policy development and assessment. That is the hope and expectation of the public health community, but it remains an open question. Other entities, private or public, could play significant roles in policy development and assessment. Entities operating in ways similar to the Joint Commission on the Accreditation of Healthcare Organizations, peer review organizations, or professional associations could claim the responsibility for assessing the quality and effectiveness of a reformed health care system. Assessing the reformed health care system will require data collection and analytical abilities that are significantly beyond most state government organizations at this time. With anti-government, anti-bureaucracy, and anti-regulatory sentiment high in the public consciousness, it is not clear that ADPH or any other department of state government would be the locus for significant new assessment responsibilities.

Currently, ADPH assessment activities center on vital events and notifiable disease monitoring. The capacity to assess these activities differs significantly from the capacity to assess the service, accessi-

bility, and effectiveness of various provider health plans. This is not to suggest that the issue of who should assess the reformed system is a foregone conclusion. Public trust, lack of self-interest, general credibility, institutional stability, and subjugation to the political process will be factors suggesting that ADPH or some other government entity should perform the assessment. Knowledge of the necessary computer capacities is not a significant problem for state governments, but finding and hiring personnel familiar with the needed analysis in the health care field is a very serious problem in Alabama (and in many other state governments).

We believe that development of standardized data sets such as the Health Plan Employer Data and Information Set (HEDIS) or the Workgroup for Electronic Data Interchange (WEDI) will provide the basis for any significant data collection efforts. HEDIS 2.0, for example, specifically includes data on childhood immunization, cholesterol screening, mammography screening, Pap smears, low birthweight, prenatal care in first trimester, emergency room visits for asthma, diabetic eye disease, and substance abuse readmission rate as qualitative measures for preventive and primary care.

MODELS FOR CHANGE

This paper presents three models or prototypes for accomplishing the transition of the personal health services of ADPH in a reformed health care system. These models are based on the economic motivation or mission of the principal entities with whom ADPH would work. That distinction is meaningful for several reasons. As a public entity, ADPH has a primary responsibility to serve the public good, and should avoid creating any financial or marketplace windfall for any private entity. In addition, partnering entities bring varying capabilities and attributes, depending on their economic and organizing characteristics. A description of the three models follows.

1. **Public model.**

ADPH could ensure that the availability and quality of its services would be attractive to patients and managed care networks in the reformed health care market by taking some or all of these steps:

(a) offering a comprehensive range of primary care services at some or all clinic sites by staffing the sites with physicians and/or nurse practitioners, or improving the accessibility and attractiveness of the less comprehensive range of services currently offered; (b) increasing investment in physical infrastructure and providing attractive facilities comparable to the private sector; and (c) developing management and personal practices to improve scheduling and waiting times, becoming more responsive to patient needs, and handling financial and referral matters at standards comparable to the private sector.

The department would be a primary and active participant in an integrated service network, health maintenance organization, or other form of managed care plan. ADPH would actively participate in all of the market developments and compete in that marketplace, perhaps "specializing" in the client group geographic areas currently served by the department. However, the political feasibility of this approach is slight or nonexistent and is unlikely to be considered for ideological reasons.

2. **Public-private model.**

ADPH would form partnerships, joint operating agreements, and/or leases with private nonprofit or for-profit operations. The principal aim would be to continue or to enhance current ADPH services without additional cost to the department. ADPH could enter into an agreement with a community hospital, university medical center, federal clinic, or private multispecialty clinic to carry out ADPH clinical operations at one or more sites. The agreement would address staffing, scope of services, and rental payment for facilities. The variety and flexibility of such agreements across the 89 clinic sites would be considerable and the administrative and legal burden of negotiating the agreements could be significant if negotiations were conducted one site at a time.

In this model, ADPH would continue to provide some direct care services. ADPH, for example, could contract to provide family planning or medical social work support not only at the ADPH clinic (which would be operated by the new ADPH partner) but also at another site (such as a community hospital) served by the new partner.

This model presents a number of possible benefits or opportunities, including (1) generating a positive financial return for ADPH through rental fees for its facilities; (2) carefully tailoring the various clinic sites to become integral parts of the primary care system; (3) negotiating the contributions of other parties to an improved system of primary care; and (4) assuring continuity of care through provision of services at the same facility by many of the same care providers, and thereby increasing the possibility of providing ancillary services (such as WIC services) at one location.

Assuming the best with respect to managed competition, we might expect that a better-organized system of primary care will emerge from the market forces and business interests already quite active in the system.

In addition, other entities can quickly bring some benefits to the system that otherwise might take ADPH some time to accomplish. A partner having a reputation identified with high-quality care, for example, could help cement patient loyalty rapidly. A partner with solid management experience in patient scheduling, billing, and collecting could be utilized quickly in ADPH clinics. Even improvement to the facilities could be accomplished quickly if negotiated as part of the agreement. Most other entities could move more rapidly than the state to contract for renovation and expend funds.

3. **Privatization model.**

In this model, ADPH and its facilities would no longer play a role in providing direct personal health care. However, to facilitate patient referrals, the transition of personal health care services from the public to the private domain should entail agreements or more informal understandings with other area providers who will be offering the services formerly provided by the department. ADPH facilities might be sold to other entities, and the terms of the sale might require assurance that primary care operations be continued for a certain period of time. Given the large and increasing number of uninsured, this model may not be possible for a large personal health care provider such as ADPH.

The disadvantage of this model is the department's loss of capacity to deliver services. If other entities come forward to provide those services, the public does not perceive a loss. However, failure of some of the new or expanded entities could result in diminished system capacity. Another disadvantage is that ADPH, once removed from the system, loses the ability to influence continued development of a good primary health care system except by direct regulation via the tools of the core public health functions.

Remaining an active player in the system (as envisioned in the first two models) would allow ADPH to continue to negotiate and influence the development of the primary care system. The policy tool of being a player in the market may well be stronger than any regulatory tool given ADPH in a reformed system. After all, most reform proposals rely principally on market models. Regulatory tools presumably would be relatively weak (and it is not certain what regulatory responsibilities might be given to ADPH).

CONCLUSION

A reformed health care system provides great opportunities to develop a much stronger primary care system. The transition, if it is to improve the system, will be difficult to accomplish in Alabama, however. It will require not only exceptionally clear vision of the goal but also the constant attention and supporting information needed to attain the goal. Assuming the best with respect to managed competition and a greatly expanded managed care environment, we might expect that a better-organized system of primary care will emerge from the market forces and business interests already quite active in the system.

We could believe, then, that most citizens will experience better primary care. However, the populations that are vulnerable, because of both geographic location and personal characteristics, may not benefit nearly so well by managed competition. I remain skeptical about the ability of market forces to serve those patients. The Alabama Department of Public Health brings to the table not only a

statewide network of clinics serving a significant portion of the population but also valuable knowledge about serving the special needs of that population. If those advantages are used along with appropriate regulatory authority and accompanying financial support to carry out the core public health functions, there is a good chance we could have a significantly improved primary care system as part of a reformed health care system.

You may wonder when I am going to say anything about the other half of the transition for ADPH—that is, developing funding to carry out the core public health functions after funds from providing personal health services are reduced or eliminated. The short answer is that I do not know the answer. There are several significant unknown factors at this time: the extent of the increased responsibilities and funds required, the amount of funding lost if ADPH ceases to provide personal health services to Medicaid recipients, and the design of the reformed system.

I offer two observations. First, significantly increased direct funding from either federal or state government is problematic. Without legislative attention to the role of public health in a reformed system, health care reform becomes particularly hazardous for ADPH.

Second, depending on the shape of reform and the responsibilities of public health, there is a potential source of politically feasible funding for public health in a reformed system. If reform includes significant use of purchasing alliances or pools, it is reasonable to fund some public health activities out of those monies. Funding part of public health in this way may be both good politics and sound policy, given the magnitude of the funds that could be involved in the purchasing pools, the off-budget nature of these purchasing pools, and the relatively small amount of funding for public health. A small portion of those funds paid to public health to support the most basic type of environmental and community health could be a significant help in funding those operations. That also moves us toward a more unified financing of health, and places in perspective the small amount of funds needed for the very large cost benefits of public health.

Clearly, public health departments that provide substantial personal health services to Medicaid-eligible patients bear a significant risk, since those patients may be moved into private managed care

operations (resulting in a withdrawal of the revenue stream from public health). Without new revenue, public health's responsibilities concerning uninsured patients and core public health functions will simply be unsustainable. As all 50 states grapple with the financial and political realities of block grants, the complexities of state-level systems will be substantial. We can be hopeful that we will have 50 successful case studies, for even a few failures could have significant adverse consequences for the life and health of the citizens in those states.

Public Health and Health Care Reform

Healthy People in Healthy Communities

This paper begins with a bias. The bias involves the imperative for an integrated system of health care, defined federally through general national parameters, and administered in the community by means of a state-local partnership involving not only government but also the private sector and providers. The system should focus on families, living in communities, with the overall goal to assure "healthy people living in healthy communities." That is the bias and the approach to public health and health care reform presented in this paper.

This paper focuses on two major themes. First, the need to integrate public health into the national agenda of health care reform is presented. Second, based on the stated bias and the assumption that it is the government's responsibility to develop and oversee a holistic system of care, the

by
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paper describes a vision-based philosophy developed by the National Association of County Health Officials (NACHO), with support from the Centers for Disease Control and Prevention.

The mission of public health, as defined in the Institute of Medicine report *The Future of Public Health* (1988), is "to assure the conditions in which people can be healthy." The mission suggests that the American public should think about "health" care rather than "illness" cure.

When considering the determinants of health, it is worth noting that lifestyle (individual behaviors) accounts for about 50 percent of what makes us healthier, what keeps us from being ill. Environmental conditions and heredity each account for only 20 percent. But, most important, medical care accounts for only 10 percent in terms of what keeps people healthy. And yet, looking at the amount of money put into the health care system, it is apparent that the United States puts most of its money into tertiary care, with much lower priority and resources given to community-based prevention, primary care, and public health services. At the same time, however, it can be argued that the cost-effectiveness is just the reverse: The most cost-effective part of the system is not the tertiary care system which serves a few, but the primary care and public health systems, which serve the population and ensure adequate preventive services for all.

The current paradigm is finally moving toward partial integration as prevention and primary care are brought into the private medical model of the personal care system.

In terms of prevention, the fact that the country has to either pay now or pay later must be underscored. Investing in prevention now (though we might not receive an immediate return this quarter, this year, or possibly even this electoral cycle) will ultimately yield greater benefits in the long term. One way of helping legislators understand this notion and begin to think about the long-term benefit is to ask them to make decisions as if they were grandparents considering decisions that would affect their grandchildren. That places the consideration some 20 to 30 years in the future and provides a long-term perspective beyond their elected term of office.

A NEW PUBLIC HEALTH PARADIGM

Having provided background, this paper will describe the current health system paradigm. A paradigm is a set of beliefs, a mind-set, or a way of thinking about things that governs attitudes, decisions, and methods of allocating resources and spending money. Our nation's current paradigm is a nonintersect of the personal, predominantly private, health care system, and of the public health care system which can be viewed as having three components—prevention, primary care, and community-based public health services.

As our nation begins to look at the problems arising from this "disconnect," three objectives for change can be identified: universal access to care, cost reductions in our trillion dollar health budget, and maintenance of quality of care. A fourth component needs to be added. First, however, the current paradigm must shift from the disconnect model and begin to integrate the personal and public health systems. The current paradigm is finally moving toward partial integration as prevention and primary care are brought into the private medical model of the personal care system. The health system is beginning to support preventive services, encourage primary care gatekeepers, and highlight managed care health maintenance organizations (HMOs).

Despite the fact that a new paradigm is evolving, issues remain. The currently evolving paradigm will not guarantee a local government health presence to assure a holistic system of care with the ability to regulate, facilitate, and evaluate health care services. There is no system to assess and respond to identified problems, to assure community well-being, and to develop and maintain a data system to monitor health and illness. Neither communicable disease surveillance nor environmental health protection is guaranteed. There is no system to focus on health education and support in the schools or workplaces where people spend most of their time.

A fourth component, therefore, must be added to the three previously stated goals of universal access, cost containment, and maintenance of quality. That fourth component should be health status improvement—not only for the individual but also for the family and the community. Public health

argues that the missing objective in the current paradigm shift is the improvement of health status. In order to accomplish this, public and private health care must be fully integrated into a prevention-oriented managed primary care and community-based protective system. That should be the focus and quest for improving our health care system and achieving the goals collectively sought.

BLUEPRINT FOR LOCAL PUBLIC HEALTH DEPARTMENTS

To begin to address implementation questions arising from such a new paradigm, the National Association of County Health Officials and the Centers for Disease Control and Prevention currently are developing a blueprint for local public health departments. During this process, NACHO envisioned a system centered upon keeping people healthy and keeping communities healthy. Our organization views this goal as fulfilling the covenant between government responsibilities and families living in communities. This is public health's social contract—to preserve and protect the health and well-being of the American people and to improve the health status of people in the community through disease prevention and health promotion.

The blueprint articulates what local health agencies seek to do in public health. Public health controls disease outbreaks, reduces environmental hazards, and manages communicable diseases. Public health immunizes children and maintains clean air and water. Public health assures safe food, provides health education and information, and provides support for vulnerable populations. What we do in public health is both important and exciting.

My home state of Maryland is creating a model of "healthy people living in healthy communities." The Healthy Marylanders model will assure a safe and healthy environment to protect against such environmental hazards as radon, asbestos, and lead in our drinking water, in paint, or in the dirt of our urban communities. This model will help to maintain clean air and water, continue the safe food handling protection that currently exists, and work to prevent epidemics, control disease, and prevent injuries.

Maryland has just initiated a new project with the State Medical Society and the Maryland Physicians Campaign Against Family Violence. Through this project, physicians will receive training in recognizing the elements of family violence, including domestic violence, child abuse, and elder abuse. Health care workers will learn to recognize signs and symptoms, create safe environments for discussion, and become aware of existing community resources. This will be accomplished through a series of train-the-trainer programs, ultimately reaching workers in 80 hospitals throughout the state.

ROLES AND RESPONSIBILITIES

The National Association of County Health Officials also believes that local health agencies have a role to play in maintaining the delivery and availability of services. Local health agencies must assure that these health care services—including preventive health care services; illness, injury, and disability services; and mental health and substance abuse services—are distributed responsibly and available for all people. Public health should assure that a safety net remains for those who are either at particularly high risk or who are part of the hard-to-reach populations such as the homeless or migrant workers. For those populations, wraparound social support services must be provided to overcome existing problems such as language and cultural barriers.

Public health must promote healthy behaviors among individuals, families, and communities. Community health education works to promote public understanding of what healthy lifestyles and behavior modification mean so that persons can make their own choices with regard to their well-being.

Public health serves the good of the people and does not barter for the bottom line.

Furthermore, local public health agencies have the responsibility to maintain and assure quality. Unlike the other players, public health has no financial stake in the system, and can be objective in striving for real quality of patient care. Public health serves the good of the people and does not

barter for the bottom line. Therefore, government should monitor the health system for high quality. Accountability must remain a function of the public domain.

Public health agencies, in order to make clear, rational, thoughtful, and competent decisions, must proceed in a scientific manner with adequate data. Information is critical to provide adequate surveillance and an early warning system to interpret trends and make appropriate decisions based on science. Public health diagnostic laboratory services are key to this process. Proactive management is needed to establish health policy and resource allocation priorities based on scientific information. A solid, well-integrated information system based on mortality and morbidity data and risk factors is needed to guide decisions about health care priorities for the future.

Public health at all levels also must invest in the technical competency of its workforce, both for today and for tomorrow. A Council on Linkages has been established wherein the schools of public health are working with state and local health officials as well as teachers of preventive medical care to encourage improved communications and integration between the delivery of health care services in the community and the training of those who will be delivering care in a changing environment. Public health must seek new methods of continuing education to strengthen the current workforce to meet the challenges of tomorrow.

Public health practitioners also must become culturally competent. Part of assuring access to services is being certain that we understand the culture of the persons using the services in order to create a comfortable environment for them. Awareness and understanding of race, ethnic, gender, and geographic differences must inform all that public health does.

The public health community must support research, discovery, and innovation for the future. Innovation and research must be considered not only for our medical and biomedical care system, but also for our social and health care delivery system.

Finally, public health must provide leadership—a shared vision of helping people to exist in healthy communities. We must define our future by defining the problem and starting with a set of objectives.

In this case, the challenges are to achieve universal access, reduce costs, maintain quality, and improve the public health status of individuals and communities. We must forego the old "disconnect" paradigm between the existing personal and public health care systems and create the new paradigm of integrating the two systems through prevention, primary care, and community-based services.

The final message is a political one—a call for adequate funding of the public health care system. A dedicated and consistent source of funding is needed. The current 0.9 percent of aggregated expenditures is inadequate. Some propose that 6 percent of the gross health care delivery budget be dedicated to public health, based on the notion that an ounce of prevention is worth a pound of cure. Many believe, however, that 3 percent would be sufficient to achieve the goals for community-based public health services. This would amount to about $25 billion to provide these public health services and make them fully operational nationwide.

If our goal is to have healthy people living in healthy communities, then it follows that integration and adoption of all of the identified elements must be achieved.

What's Needed to Move Forward? State MCH Program Perspectives

I've been thinking about my role as synthesizer of all the conversations we have had over the last two days, as I attempt to answer the question: "What is needed to move forward?" Indeed, this may be the most challenging job of all!

In considering capacity implications for MCH under a reformed system where it is anticipated that most will have access to primary care, I found a useful way to frame both the questions and the answers: Focus on Dr. Starfield's taxonomy of the health services system within public health (see p. 17) and, from an MCH perspective, ask: "What structures, what processes, what outcomes are needed to accomplish the mission of promoting and protecting the health of the MCH populations in our communities?"

by
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STRUCTURE

Historically, health departments have been organized around categorical funding streams. Departments literally have been built around categorical functions, often with very narrow program-specific perspectives. Adequate capacity in many core functions has been hampered by constraints on categorical dollars. To play an effective role in a reformed system, the vision for maternal and child health, and for all of public health, demands strong leadership in the areas of systems development, quality assurance, service coordination, population-based assessment, and planning.

I foresee a tremendous shift from concentration on direct service delivery to masterful ability to execute core public health functions. The implications for MCH in the context of public health and reform are enormous. Beginning with a new way of organizing our human and fiscal resources, MCH will have to retool staff for new roles, deploying those uncomfortable with change to the private sector.

By way of example, the Washington State Department of Health took a bold step on December 1, 1993, by reorganizing entirely around the core public health functions of assessment, policy development, and assurance.[1] After virtually all of the state's 33 health departments and districts participated in APEX Part I, and a fair number in APEX Part II, it became clear that we lacked adequate capacity in any of the core functions, but particularly in the area of assessment. Data information systems as well as epidemiological and statistical analysis and support were very limited. We realized that if health departments, both state and local, were going to have a future, we needed to get serious about core functions.

The Department of Health currently has an epidemiology and health statistics division, a health systems quality assurance division, an environmental health division, a public health laboratory division, and a community and family health division. Basically all of the personal service functions are now in the community and family health division. We are attempting to break out of our categorical

boxes by doing a lot more planning across program areas and defining problems more broadly. In addition, a central policy unit is part of the Office of the Secretary. Only time will tell whether these macro structural changes will improve our ability to be more responsive to public health problems under reform; at the moment, we feel that these were necessary changes.

Within MCH, we are analyzing what clinical personal services we currently subsidize that might be financed under our state's health reform law, in the Uniform Benefits Package, and we are surveying the skills base for a different type of technical assistance and consultation. We envision training staff in areas of planning; needs assessment; health information systems that track and monitor health status; standards; quality assurance; and program evaluation.

I foresee a tremendous shift from concentration on direct service delivery to masterful ability to execute core public health functions.

With Washington State's passage of a comprehensive health reform act in May 1993,* we also recognized the need to forge relationships with new and evolving entities in the private sector, and to sustain relationships with public sector entities such as Medicaid, social services, and education. Skills in facilitation, effective communication, negotiation, and community mobilization, as well as an understanding of managed care networks, are viewed as extremely valuable. Historically, the MCH program has had the capacity to provide technical assistance and consultation in the clinical areas. In the future, we need to have adequate skills to assist local health jurisdictions in the nonclinical areas of planning, organization, and administration during the transition from personal service to population-based activities. Fortunately for maternal and child health (unlike some of the other categorical programs in

* Although this legislation was later repealed, many of the functions outlined for the public health agency were retained and continue to receive legislative and public support.

public health), the Omnibus Budget Reconciliation Act of 1989 (OBRA '89) charted a course toward systems development capacity, so this trend is already in place or under way.

PROCESS

Increasingly, public health will need to have adequate processes in place for recognizing and defining existing and emerging problems. This means adequate capacity for continuous and reliable monitoring of health-related risk factors (or protective factors) that affect entire communities.

The MCH contribution to ongoing surveillance and tracking systems requires competent human resources—that is, dedicated staff to design, manage, and maintain information systems that today are simply nonexistent in many communities or at the state level. In Washington State, we are building this critical capacity beginning at the ground floor. Some systems may need to be regionalized. As we sort through the provision of care based on need and the receipt of care based on individual and community understanding of the value of prevention and wellness, we need to remember Dr. Mike McGinnis' recent challenge[2] to the public health community to begin looking at the real causes of premature death and disability—tobacco, alcohol, injury, poor diet, lack of exercise, and unprotected sexual activity. When we do this, we realize that if we are to influence health status, our "process" thinking must center on interventions that change behaviors.

OUTCOME

Ultimately, public health must answer the question: Has the reformed health system improved the health status of communities? To answer this question, a good assessment of health status must be documented before, during, and after changes in the system. Evaluation measures over time and monitoring of trends over time are areas where public health must build adequate capacity.

Additionally, policymakers will be interested in cost, so monitoring investments in prevention also will be very important. Typically, program evaluation and measurement of health services effectiveness have not been strong areas in health departments. One certain implication of reform is a strengthened public health role in this area. For MCH, this again means staff with ability to work very closely with applied epidemiology across programs and disciplines in order to develop means and measures to track health status.

Information systems development has become extremely critical as we envision our future role. Fortunately, the health reform legislation in our state recognized how critical information systems will be for Washington State and included statutory language mandating that the Department of Health become the reservoir of all health services information; the legislation also authorized funding to begin planning for a health services information highway. The Health Services Information System in Washington State is being designed as an integrated, statewide information system that will:

- Provide largely decentralized services, with some centralized information repositories and with integrated data sets;
- Support key internal information needs and external reporting requirements of a broad variety of system uses;
- Use a standard, statewide data dictionary that has existing data standards built-in and that is compatible with national reform;
- Offer online availability and real time where feasible;
- Support continuous quality improvement for the health care system as a whole; and
- Include incremental and cost-effective implementation.

As mentioned earlier, public health is in need of a consistent, reliable funding stream that is not bogged down with categorical restrictions. Washington State is addressing this issue through the *Public Health Improvement Plan*[3]—a document outlining what public health will need in the way of resources, both human and fiscal, to reach adequate capacity at state and local levels in six areas:

administration, assessment, policy development, promotion, prevention, and protection. We have attempted to delineate by personnel (full-time employees) and funding what we judge to be adequate capacity in these areas. To date, we are still refining these estimates; however, a review of our work is at least a place to begin.

The key to all of this is financial support through our state legislature to build and maintain capacity for implementing core functions in all health jurisdictions. We cannot do it without money. For reform to work, public health has to be financed adequately. Fortunately, Washington State's reform legislation has built-in provisions for public health. (This has not been true in other states or in national reform.)

In summary, I anticipate that state health agencies will likely become smaller over ensuing years. Structurally, these agencies will look different because their primary agendas will be to carry out more and more population-based core function activities, with little involvement in the actual delivery of clinical personal health services. Because presumably there will always be gaps in service for vulnerable populations, some personal health services currently delivered through public health—particularly those involving significant threats to entire populations (e.g., sexually transmitted diseases, tuberculosis, HIV/AIDS)—probably will remain in public health indefinitely.

For MCH specifically, I envision structural changes that support a smaller staff, with focus on functions in planning, assessment, program evaluation, quality assurance, and increased coordination at all levels with systems outside of health (such as education, welfare, mental health, drug and alcohol abuse, social services, and a variety of private and public community-based organizations). There are enormous opportunities for MCH in the midst of all this change. By way of example, the MCH-supported staff of one local health department in our state has already begun to make these changes.

I am excited by the future, though surrounded by a host of new challenges. Each state will be trying to figure out the structures, the processes, and the outcomes best suited for its population. I am hopeful that what I have been able to share will have some utility as we all carve out the future of MCH, along with the future of all of public health under reform.

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Commentary and Closure

This workshop was planned and held in anticipation of health care reform, by which we meant the passage of federal health care legislation that might fundamentally alter the health care delivery system. As we all know, such legislation, including the President's proposed Health Security Act of 1994, was not enacted. We are witnessing, instead, what may be even more profound changes in the delivery of health care services. These changes are based fundamentally in the private sector and represent the increasingly corporate nature of health care delivery, particularly through the expansion of managed health care plans.

In a sense, then, we were at the right track but had bet on the wrong horse. The concepts developed at the workshop will be just as useful for assessing the impact and development of systems

by
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of privatized managed care for children as they would have been for guiding the development of a federally mandated system.

The purpose of this commentary is to bring closure to the workshop proceedings, reflect on what we have learned, and identify directions for the future. How can we use the ideas and experience brought to this forum to guide the work of federal, state, and local MCH agencies in the future? What are the major themes, and the next steps to be pursued?

A "SYSTEMS" FRAMEWORK

The antecedents of the workshop include the Omnibus Budget Reconciliation Act of 1989 (OBRA '89) amendments to Title V; these amendments charge the federal and state MCH agencies with responsibility for meeting the primary health care needs of children and youth and for building community-based systems of care. We anticipated using the workshop proceedings to guide the state and local MCH agencies in developing their role in relation to health care reform. The mandate and objectives for the workshop are in no way diminished, however, by the failure to enact federal health care reform legislation. If anything, the tasks of designing the roles of public MCH agencies in an era of organized, privately owned managed health care systems become more challenging and important in the future.

The framework for this commentary returns to an earlier discussion of the characteristics of a "system." Here, we propose to examine each characteristic of a system of health care and identify the important implications for the work of maternal and child health. Ironically, the emerging managed care industry is already oriented toward using the systems language and management approaches in thinking about its own development. The task becomes to orient the public agencies to thinking in this manner.

As noted in an earlier chapter (see page 9), systems are characterized by three major features: First, systems have a shared goal or purpose; second, systems are made up of differentiated components

that complement each other; and, third, the components of a system communicate with each other to assure that the goal is met. What have we learned from the workshop proceedings in relation to each of these features? How can we use this framework to help us guide future work?

SHARED GOALS

If a system is to have a common goal, then the goal must be articulated and shared by the private and public sectors. The Title V legislation sets broad goals for child health in this country, and *Healthy People 2000* articulates these goals in specific, measurable objectives for health status and health care utilization. These national goal statements are clearly population oriented and encompass all children and their families.

In the developing managed care systems, however, goals are set for defined groups of enrolled subscribers, not for entire populations within geographic jurisdictions. Managed care organizations are not likely to accept responsibility for nonenrollees. Thus, a major function of the MCH agencies will be to maintain the population focus. The MCH agencies must set goals for the entire population and remain particularly cognizant of those subpopulations that are likely to fall through the cracks in the system. These populations are likely to include the disadvantaged low-income working families without health insurance, minorities, legal immigrants and undocumented workers, and rural and migrant children, among others. In addition, managed care organizations are likely to crisscross geographic jurisdictions in complex and overlapping ways. Thus, MCH agencies will need to work with multiple managed care organizations to assure awareness of population-based health goals and coordination of efforts to address these goals. Finally, subscribers will have opportunities to change managed care plans, creating the potential for gaps in coverage. Health care services will need to be assured during these temporal gaps. Overall, a crucial function of the MCH agency will be to assess community needs and assure that the multiple and overlapping managed care organizations maintain adequate coverage so that each child has access to a system of care.

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Another major goal of maternal and child health in the emerging managed care environment is to assure the development, acceptance, and implementation of a child-specific standard of need. Without such an explicit standard, it is unlikely that managed care organizations will guarantee health care services that meet the unique needs of their child subscribers. The key elements of a standard of need for children have been articulated by Jameson and Wehr. The rationale for such a specific standard includes the fact that children are dependent and need their families and community institutions to look out for their well-being. Children are in a state of continual and often rapid development so that the services provided to them must include not only maintenance of health but promotion of optimal development. Finally, children have different epidemiological conditions than adults. Health care systems must provide for these particular epidemiological patterns. MCH agencies must work to establish such children's standards of need and then assure that the standards are met by all providers.

COMPONENTS OF A HEALTH CARE SYSTEM

Starfield has articulated the components of a primary care system for children. The attributes of primary care provide the framework for these components. *First-contact care* is intended to be a gatekeeping function that not only keeps children out of the emergency room for nonurgent care, but also assures that a primary care site is aware of and directing all of the health care decisions concerning these children. *Longitudinality* requires a single provider to serve as the medical home and maintain ongoing contact with the family. *Coordination* implies a responsibility for managing elements of care provided in a variety of settings and assuring the appropriate level of communication between the settings. *Comprehensiveness* requires that health care systems be able to provide the range of services appropriate to the broad health care needs of a childhood population. This is an area of particular concern because of the cost implications of maintaining relationships with pediatric specialists to serve low-incidence conditions. *Cultural competence* is not an optional feature of the health care system, but, rather, a fundamental component assuring that health care providers are aware of the culturally determined health care beliefs and practices that will result in effective use and treatment.

Family-based care assures that families participate in the care and decision making about their children. Finally, *community-oriented care* is needed to relate children's health care needs to the variety of environmental influences and community resources with implications for child and family.

These components of an effective primary care system must be present if the system is to yield the kinds of positive outcomes that have been documented in many European countries. It is clear from the workshop presentations that such primary care systems can be delivered from a variety of institutional bases and through a variety of creative arrangements between public and private sectors. Clearly, however, children's health specialists at the primary, secondary, and tertiary levels must be involved in the development of such systems. The standard-setting regulatory and contractual authorities of public MCH agencies at the state and local levels are the tools of government that can be used to build such a system.

Public MCH agencies themselves must become an integral component of the community-based health care system. When universal health care coverage is achieved, these agencies will no longer provide direct health care services (as they once did) to women and children, including children with special needs. However, as providers of some direct services in special settings (such as schools), as purchasers of services, and, finally, as official agencies with assessment, assurance, and policy functions, the MCH agencies must become part of the emerging network of health care.

COMMUNICATION BETWEEN THE COMPONENTS

Fundamental to systems theory is the notion that the components of a system communicate among each other to meet the common objective. At the basis of such communications are timely data systems that measure key variables, make a patient-specific database (information system) available to practitioners, and monitor indicators of utilization and health status. Managed health care organizations already monitor patient data for fiscal purposes and usually maintain a computerized medical record. Such efforts must be expanded to include the data elements necessary to assure that the system is working for the benefit of children.

Walker and others have described the ways in which data systems can be used to assure maternal and child health services. Above all, MCH agencies must hold the health care system accountable for the ways in which it serves the best interests of children. Good data systems are at the heart of the accountability functions of government. Good data also must be made available to the public and to policymakers at the community level to allow them to monitor system performance.

FUTURE DIRECTIONS

Few of us would have accurately predicted the outcome of the great health care debate of 1993–94, making the identification of future directions somewhat problematic. It seems evident, however, that future development of the health care system will be driven by the major societal forces—including shifting demographics that will emphasize the care of adults and the elderly, further efforts to curb the growth of health care costs and their burden on business and industry, and less dependence on the regulatory mechanisms of government coupled with more dependence on the marketplace—to guide services development. In this environment, it is the responsibility of advocates for children to make the case for the benefits of organized systems of primary care as the foundation for the adequate development and health of our children. Some observers have made the case for an investment strategy—namely, that we must invest in the health and development of our children if the nation is to have a strong and secure future.

The academic, advocacy, and provider communities must join forces to become effective spokespersons for the health and developmental needs of children. The arguments for strong primary care systems and for effective governmental MCH agencies must be based on the kinds of arguments and experiences expressed during this workshop. Future work must include efforts to experiment with new forms of health services delivery, evaluations of the multitude of natural experiments currently under way across the nation, and further research into the systems characteristics that best serve the needs of children and families. We must build up a strong database to assess and monitor for our children the implications of systems changes of all types. These experiences will form the substrate for future efforts at health care reform.

Agenda

Workshop on Assessment and Development of Primary Care for Children and Youth
Doubletree Inn at the Colonnade – Baltimore, MD

WEDNESDAY, APRIL 20, 1994 – DEFENSE & NAIAD ROOMS

8:15 AM REGISTRATION AND CONTINENTAL BREAKFAST

9:00 AM Defining the Issues and Planning for Change: Systems, Primary Care and Reform

David Heppel, M.D.
Director, Division of Maternal, Infant, Child, and Adolescent Health
Maternal and Child Health Bureau, HRSA, PHS, DHHS

9:20 AM Overview and Context: Health Care Systems and Primary Care for Children and Adolescents

Bernard Guyer, M.D., M.P.H., and Barbara Starfield, M.D., M.P.H.
JHU Child and Adolescent Health Policy Center

10:10 AM BREAK

10:30 AM Delineating Public Roles in Planning, Providing, and Evaluating Primary Care Services for Children and Their Families

David R. Smith, M.D.
Commissioner of Public Health, Texas State Health Department

11:15 AM Questions, Comments, and Discussion: How Can Public Agencies Be Effective Stimulators of Primary Care Systems Development?

Discussion Leaders
Thomas DeWitt, M.D., Massachusetts Medical Center
Modena Wilson, M.D., M.P.H., Johns Hopkins Hospital
James Perrin, M.D., Massachusetts General Hospital

12:00 PM LUNCHEON

1:00 PM Assessing the Status of Primary Care Services — A Working Approach

Barbara Starfield, M.D., M.P.H.
JHU Child and Adolescent Health Policy Center

2:00 PM BREAK

2:15 PM Discussion Panel: Primary Care Assessment, Planning and Evaluation — State and Local Approaches, Experiences, and Perspectives

- Possibilities Found in Use of National, State, and Local Population Data Sets
  Deborah Klein Walker, Ed.D.
  Assistant Commissioner, Massachusetts Department of Public Health, Bureau of Parent, Child and Adolescent Health
- SHA/CHC Initiatives in Assessing Need and Tracking Progress in the Delivery of Primary Care
  Rita Goodman, M.S., R.N.C., F.N.P.
  Nurse Consultant, Bureau of Primary Health Care, HRSA, PHS, DHHS
- Community System Assessment and Child Health Planning in Iowa
  Charles Danielson, M.D., M.P.H.
  Medical Director, Division of Family and Community Health
  Iowa Department of Public Health
- Evaluating the Delivery of Pediatric Primary Care in New York City
  Lucille Rosenbluth, M.P.A.
  President, Medical and Health Research Association of New York City, Inc.

3:15 PM Questions, Comments, and Discussion

Discussion Leader
Donna Strobino, Ph.D.
JHU Child and Adolescent Health Policy Center

3:45 PM BREAK

4:00 PM Defining and Operationalizing Accountability in Primary Health Care Systems—Theoretical Constructs and Research and Policy Challenges

Bernard Guyer, M.D., M.P.H.
JHU Child and Adolescent Health Policy Center

5:00 PM ADJOURN FOR THE DAY

THURSDAY, APRIL 21, 1994 — DEFENSE & NAIAD ROOMS

8:00 AM CONTINENTAL BREAKFAST

8:30 AM Overview of the Day's Agenda: Implementation Challenges

Holly Allen Grason, M.A.
Director, JHU Child and Adolescent Health Policy Center

8:45 AM Developing Community Capacity for Primary Care
Private Sector Primary Care Practitioner Issues and Needs

— Family Practice Perspectives
Larry Culpepper, M.D.
Director of Research and Associate Professor of Family Medicine
Memorial Hospital of Rhode Island
Representing the American Academy of Family Practitioners

— Pediatricians' Views
Susan Aronson, M.D., F.A.A.P.
Clinical Professor of Pediatrics
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Representing the American Academy of Pediatrics

9:40 AM *Models and Implications for Local Public Health Agencies*

— CHIP - A Community Model for a Comprehensive Health Care System
Peggy Balla, R.N., M.P.H.
Project Director, Child Health Investment Partnership
Roanoke, Virginia

10:10 AM BREAK (Checkout)

10:35 AM Opportunities, Roles, and Strategies for States

— Pediatric Primary Care Systems Development Initiatives in Arizona
Jane Pearson, R.N.
Assistant Director, Arizona Department of Health Services

— Health Care Reform and Public Health Considerations in Alabama
Larry Menefee, J.D., M.P.H.
Staff Director, Alabama Health Care Reform Initiative

11:30 AM Questions, Comments, and Discussion

Discussion Leader
Phyllis Stubbs, M.D., M.P.H.
Maternal and Child Health Bureau

12:15 PM LUNCHEON

1:15 PM Capacity Implications for State and Local Public Health Programs: What's Needed To Move Forward?

— Local Public Health Agency Views
Martin Wasserman, M.D., J.D.
Director, Prince George's County Health Department, Maryland

— State Maternal and Child Health Program Perspectives
Maxine Hayes, M.D., M.P.H.
Assistant Secretary, Parent and Child Health Services
Washington Department of Social and Health Services

2:15 PM Questions, Comments, and Discussion

2:30 PM Workshop Conclusions: A Primary Care Agenda for Child Health Research and Practice

Barbara Starfield, M.D., M.P.H.
JHU Child and Adolescent Health Policy Center

David Heppel, M.D.
Director, Division of Maternal, Infant, Child and Adolescent Health
Maternal and Child Health Bureau

Bernard Guyer, M.D., M.P.H.
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3:00 PM MEETING ADJOURNS

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